

FACTORS AND COPING STRATEGIES THAT IMPACT CHILDREN AND
ADOLESCENTS WITH ALOPECIA AREATA: AN EXPLORATORY FACTOR
ANALYSIS

Janice J. Wolf
A Dissertation
Submitted to the
Graduate Faculty
of
George Mason University
in Partial Fulfillment of
The Requirements for the Degree
of
Doctor of Philosophy
Education and Human Development

_____ Chair

_____ Program Director

_____ Dean, College of Education
and Human Development

Date: _____ Spring Semester 2014
George Mason University
Fairfax, VA

Factors and Coping Strategies that Impact Children and Adolescents with Alopecia
Areata: An Exploratory Factor Analysis

A Dissertation submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy at George Mason University

by

Janice J. Wolf
Masters of Education
George Mason University, 2007
Bachelor of Nursing
George Mason University, 1984
Bachelor of Business Education
Bowling Green State University, 1976

Director: Pamela Hudson Baker, Associate Professor
Education and Human Development

Spring Semester 2014
George Mason University
Fairfax, VA



This work is licensed under a [creative commons attribution-noncommercial 3.0 unported license](https://creativecommons.org/licenses/by-nc/3.0/).

DEDICATION

This research is dedicated to the children and adolescents who are adapting to and managing their altered appearance due to alopecia areata.

ACKNOWLEDGEMENTS

Thank you to my amazing committee. It was a pleasure and honor to work with you. I would like to express my deepest gratitude to Dr. Pam Baker for accepting this challenge, organizing ideas for the project, and mentoring me with patience and understanding. Appreciation also goes to my methodologist, Dr. Galluzzo for his excellent and invaluable guidance in directing this study. Dr. Urban, thank you for your encouragement, medical expertise, and for supporting my effort to change the lives of children and adolescents with alopecia areata.

Thanks also to NAAF for their support and accessibility throughout this study.

A special thank you to my boys Steve and Doug (and Doug's wife Kelly) for their loving support, continuous encouragement, and understanding when dinners and family events were missed.

Finally, thank you to all my family and friends who supported me on my yearly progress and cheered for my successful completion of this study.

TABLE OF CONTENTS

	Page
List of Tables	ix
List of Figures	xii
Abstract	xiii
1. Introduction	1
The Cycle of Alopecia Areata.....	3
Children and Adolescents with Alopecia Areata	4
Treatments.....	8
Statement of the Problem.....	9
Rationale	11
Purpose of the Study	13
Research Questions.....	13
Significance of the Study	14
Definition of Terms.....	15
Assumptions.....	16
Delimitations.....	17
Summary	18
2. Literature Review.....	19
Characteristics of Alopecia Areata	20
Alopecia Areata and the Immune System.....	22
Variations of Alopecia	24
Across Genders	25
Potential Impact Factors	28
Potential Types of Coping Strategies.....	42
Medicinal Treatments	42
Alternative Treatments.....	45
Cosmetic Cover-up.	48

Community and Outside Support.....	50
Communication/Technology.....	51
Family Support.....	52
Summary	57
3. Methods.....	58
Research Design.....	58
Sampling	60
Ethical Considerations	60
Survey Development.....	62
Survey Validation	64
Revised Survey	67
Independent Variables	68
Dependent Variables.....	69
Piloting of Survey	71
Potential Participants	72
Procedures.....	73
Outcomes	74
National Distribution of Survey.....	74
Potential Participants	75
Procedures.....	76
Outcomes	77
Qualitative Follow-up	78
Potential Participants	79
Procedures.....	79
Outcomes	83
Qualitative Reliability and Validity	84
Data Analysis	85
Summary	90
4. Results.....	91
National Study	92
Click-through Rate.....	92
Participants.....	93

Research Question 1	97
Research Question 2	102
Research Question 3	107
Comparing Gender and Duration Factors	107
Comparing Age and Onset with Impact Factors.....	111
Research Question 4	121
Comparing Gender and Duration with Types of Coping Strategies	121
Comparing Age and Onset with Types of Coping Strategies.....	125
Research Question 5	135
Research Question 6	140
Research Question 7	143
Personal Experiences	147
Stories.....	147
Lessons learned.....	149
Emergent Themes	150
Coping.....	153
Acceptance.....	155
Social issues	156
Additional Connections	158
Summary	159
5. Discussion	161
Observations about Participant Demographics.....	162
Conclusions and Implications Regarding Impact Factors	163
Impact Factor 1 (Confidence/Self-esteem).....	164
Impact Factor 2 (Psychological Effects).....	165
Impact Factor 3 (Appearance/Acceptance).....	167
Impact Factor 4 (Socialization).....	168
Impact Factor 5 (Communication	169
Conclusions and Implications Regarding Types of Coping Strategies.....	170
Type of Coping Strategy 1 (Physiological).....	172
Type of Coping Strategy 2 (Cover-up/Avoidance).....	173
Type of Coping Strategy 3 (Outside Support).....	174

Type of Coping Strategy 4 (Social Network).....	176
Type of Coping Strategy 5 (Family Support).....	177
Qualitative Insights	178
Acceptance with Links to Impact Factors.....	179
Social Issues with Links to Impact Factors.....	181
Types of Coping Strategies Linked with Factors.....	184
Limitations	190
Recommendations.....	192
Future Research	194
Final Remarks	197
Appendices.....	199
Appendix A.....	200
Appendix B	201
Appendix C	202
Appendix D.....	208
Appendix E	214
Appendix F.....	220
Appendix G.....	227
Appendix H.....	232
Appendix I	238
Appendix J	244
Appendix K.....	245
Appendix L	246
Appendix M	247
References.....	249
Biography.....	264

LIST OF TABLES

Table	Page
Table 1. Literature Review-Based Impact Factors	55
Table 2. Literature Review-Based Coping Strategies.....	56
Table 3. Summary of Independent and Dependent Variables with Corresponding Questions.....	70
Table 4. Follow-up Individual Interview Criteria.....	80
Table 5. Data Analysis Summary	86
Table 6. Click-through Response Rate	92
Table 7. Demographic Characteristics of Participants.....	94
Table 8. Eigenvalue and Percentage of Variance Explained by Each Impact Factor	97
Table 9. Five Identified Impact Factors.....	99
Table 10. Component Loadings for the Rotates Solution by Size – Impact Factors.....	100
Table 11. Eigenvalue and Percentage of Variance Explained by Each Type of Coping Strategy.....	103
Table 12. Five Identified Types of Coping Strategies	104
Table 13. Component Loadings for the Rotated Solution by Size – Types of Coping Strategies	105
Table 14. A Comparison of Gender and the Five Impact Factors	109
Table 15. A Comparison of Duration and the Five Impact Factors.....	111
Table 16. ANOVA Age Group Comparisons of Impact Factor 1 (Confidence/Self-Esteem).....	112
Table 17. ANOVA Age Group Comparisons of Impact Factor 2 (Psychological Effects)	113
Table 18. ANOVA Age Group Comparisons of Impact Factor 3 (Appearance/Acceptance).....	114

Table 19. ANOVA Age Group Comparisons of Impact Factor 4 (Socialization)	114
Table 20. ANOVA Age Group Comparisons of Impact Factor 5 (Communication)	115
Table 21. ANOVA Summary Table of Age Groups and Impact Factors	116
Table 22. ANOVA Onset Comparisons of Impact Factor 1 (Confidence/Self-Esteem)	117
Table 23. ANOVA Onset Comparisons of Impact Factor 2 (Psychological Effects)	118
Table 24. ANOVA Onset Comparisons of Impact Factor 3 (Appearance/Acceptance)	119
Table 25. ANOVA Onset Comparisons of Impact Factor 4 (Socialization)	119
Table 26. ANOVA Onset Comparisons of Impact Factor 5 (Communication)	120
Table 27. ANOVA Summary Table of Onset and Impact Factors	121
Table 28. A comparison of Gender and Type of Coping Strategy	123
Table 29. A Comparison of Duration and Type of Coping Strategy	125
Table 30. ANOVA Age Group Comparisons to Type of Coping Strategy 1 (Physiological)	126
Table 31. ANOVA Age Group Comparisons to Type of Coping Strategy 2 (Cover-up/Avoidance)	127
Table 32. ANOVA Age Group Comparisons to Type of Coping Strategy 3 (Outside Support)	127
Table 33. ANOVA Age Group Comparisons to Type of Coping Strategy 4 (Social Network)	128
Table 34. ANOVA Age Group Comparisons to Type of Coping Strategy 5 (Family Support)	129
Table 35. ANOVA Summary Table of Age and Type of Coping Strategy	130
Table 36. ANOVA Onset Comparisons to Type of Coping Strategy 1 (Physiological)	131
Table 37. ANOVA Onset Comparisons to Type of Coping Strategy 2 (Cover-up/Avoidance)	132
Table 38. ANOVA Onset Comparisons to Type of Coping Strategy 3 (Outside Support)	132

Table 39. ANOVA Onset Comparisons to Type of Coping Strategy 4 (Social Network).....	133
Table 40. ANOVA Onset Comparisons to Type of Coping Strategy 5 (Family Support).....	134
Table 41. ANOVA Summary Table of Onset and Type of Coping Strategy	135
Table 42. Impact Factor Frequencies	138
Table 43. Coping Strategy Frequencies	142
Table 44. Follow-up Individual Interview Respondents.....	143
Table 45. Individual Interview Schedules	144
Table 46. Demographics of Interview Participants.....	147
Table 47. Comparisons between Literature and Impact Factors.....	164
Table 48. Comparisons between Literature and Types of Coping Strategies.....	171
Table 49. Qualitative Themes	179

LIST OF FIGURES

Figure	Page
Figure 1. Concept Map of Emergent Themes.....	152
Figure 2. Word Cloud from Interview Scripts.....	159

ABSTRACT

FACTORS AND COPING STRATEGIES THAT IMPACT CHILDREN AND ADOLESCENTS WITH ALOPECIA AREATA: AN EXPLORATORY FACTOR ANALYSIS

Janice J. Wolf, Ph.D.

George Mason University, 2014

Dissertation Director: Dr. Pamela Hudson Baker

People are often curious, and concerned when encountering individuals who are losing or have lost all of their hair. While hair loss is mostly associated with individuals undergoing chemotherapy, alopecia areata (AA) also causes individuals to lose the hair on their scalp and elsewhere on the body. This loss can be particularly devastating to children and adolescents, and can affect their psychological well-being. This research proposed to explore the factors that impact children and adolescents with AA as well as the coping strategies they use. A mixed method research design was used to combine survey data with interview transcripts and field notes to capture a more detailed picture of AA and its effect on children and adolescents. The 56-question survey included nine demographic items, four independent variable items (age, gender, age of onset, duration of diagnosis) and 43 dependent variable items (28 assessing impact factors, 15 assessing coping strategies). The interview protocol included seven questions with field notes that

helped to document observations indicating appearance, emotions, and body language. Two exploratory factor analyses revealed five impact factors and five types of coping strategies, which linked to both the literature overview and qualitative findings. The impact factors identified were: Confidence/Self-Esteem, Psychological Effects, Appearance/Acceptance, Socialization, and Communication. The coping strategies identified were: Physiological, Cover-up/Avoidance, Outside Support, Social Network, and Family Support. Female participants reported significantly greater difficulty adjusting and managing AA than did their male counterparts. No significant differences were present based on having AA for a short time or a long time. Younger participants expressed significantly lower psychological impacts than did mid-level or older participants. Participants with later onset of AA reported having a significantly more difficult time adjusting to their new appearance than those having earlier onset. The item offering the greatest frequency of response overall was the support of family and friends. The prompt, *My family help support me* received a 98% (agree/strongly agree) response. The least frequently cited response was to the question, *I have had individual counseling for my AA* at 22.4% (agree/strongly agree). The emergent themes from the qualitative analysis centered on the topics of: Acceptance, social issues, and coping. Providing education and awareness can help alleviate misconceptions about this condition.

1. INTRODUCTION

The word alopecia has a Greek origin meaning, “fox mange,” but contemporary medical sources describe it as, “Absence or loss of hair, esp. of the head” (Taber’s Cyclopedic Medical Dictionary, 2013, p. 88). Alopecia areata (AA) is an autoimmune disease that results in the loss of hair on the scalp and elsewhere on the body and does not discriminate between genders or ages, is unpredictable and has no known cure (MacLean & Tidman, 2013; Papadopoulos, Schwartz, & Janniger, 2000). An autoimmune disease is produced when “the body’s normal tolerance of the antigens of its own cells is disrupted” (Taber’s Cyclopedic Medical Dictionary, 2013, p. 236). In the case of AA, hair follicles are attacked by the person’s own immune system. More questions than answers exist regarding this condition and it is thought to be influenced by environmental factors as well as having a genetic cause (Lu et al., 2006; Madani & Shapiro, 2000). AA is also thought to have an association with other autoimmune diseases including, but not limited to: (a) diabetes mellitus, (b) lupus erythematosus, (c) vitiligo, (d) thyroid disease, and (e) Down’s syndrome (Finner, 2011; Kakourou, Karachristou, & Chrousos, 2007; Thomas & Kadyan, 2008). This disease is not life threatening but can only be treated, not cured (Hunt & McHale, 2005b).

AA is “the most commonly seen noninfectious hair loss disorder in children . . . it can occur in the first months of life, but usually occurs in school-aged children” (Hilton,

2001, p. 21). Mounsey and Reed (2009) state that it can occur at any age, and 30% to 48% of young people with AA acquire this disease before they are 20 years old. More research needs to be conducted in this area, according to Kakourou et al. (2007), as studies on children with AA have been limited. In addition, the National Alopecia Areata Foundation (NAAF) states that children are affected most often with this condition (NAAF, 2011a) and over five million people in the United States are affected (NAAF, 2011d).

Females with AA have more difficulty accepting their hair loss than do men, whose baldness is seen as more socially acceptable (Vandegrift, 1994). Hair loss in women can be upsetting and unwelcome as hair is important to a woman's appearance and identity (Sinclair, 2011). Hair has an overwhelming impact on women's self-perception because of numerous cultural and social implications (Tucker, 2012). The loss of hair can be interpreted as a social statement, religious preference, or a health concern (Freedman, 1994) and many women feel the need to disguise the loss. Cash, Price, and Savin (1993), suggest that women place more emphasis on their looks than do men in an effort to look more attractive and normal. On the other hand, Cash (2009) completed a study on the attitudes and behaviors of men with male pattern hair loss and found that they also experienced negative psychological effects from losing their hair.

The NAAF supports individuals with AA; this group organizes support groups throughout the United States. They are also leading worldwide research efforts to determine causes and find treatments for AA. The Food and Drug Administration has not approved any treatment specifically for AA; however, treatments used for AA have been

approved for other conditions (NAAF, 2011d). In addition, the Children's Alopecia Project (CAP) also supports children and adolescents with AA by raising awareness, providing support to families, building self-esteem, and supporting research (Children's Alopecia Project, 2012).

The Cycle of Alopecia Areata

AA usually begins with a small round smooth bald patch that may eventually fill back in with hair. Although this patchy alopecia (AP) may be the extent of a person's experience with AA, it may also progress to more severe forms, referred to as alopecia totalis (AT), total hair loss on the scalp, or alopecia universalis (AU) complete loss of body hair (Welsh & Guy, 2009). These symptoms may also be accompanied by fine pitting of the nails, thin or brittle nails, as well as longitudinal ridges on the nail (Gilhar et al., 2012; Papadopoulos et al., 2000). A dermatologist can usually identify this disease by looking for the classic "exclamation point" hairs, which show a club-shaped hair root (Nield, Keri, & Kamat, 2006).

Several clinical variations of this disease also exist. Ophiasis alopecia areata is a band-like area of hair loss from above the ear around the back of the head to the other ear. Reticular alopecia areata is patches of hair loss at different stages of the disease (Papadopoulos et al., 2000). Nield et al. (2006) refer to four more common alopecias: (a) tinea capitis occurs due to an infection on the scalp; (b) traction alopecia occurs when there is damage to the hair due to hair styling (e.g., tight ponytails); (c) trichotillomania occurs when a person intentionally pulls out his/her own hair, which may be due to a

psychiatric disorder; and (d) telogen effluvium occurs when one experiences emotional or physical stress (ex. serious illness, crash diets).

AA is a common condition that does not single out age groups, genders, or races (Papadopoulos et al., 2000). In a study completed in Minnesota, the age range at the time of an initial diagnosis for this condition was from 1 to 91 years (Safavi, Muller, Suman, Moshell, & Melton, 1995). AA is unpredictable, and what triggers the immune system is unknown. Research has shown that some genetic markers have been found. The genes found in individuals with AA, “are also involved in other autoimmune diseases, including rheumatoid arthritis, type 1 diabetes and celiac disease” (NAAF, 2011d, p. 4). Family members of an individual with AA have an 8.4% to 18% chance of developing this disease (Kakourou et al., 2007). MacLean and Tidman (2013) suggest there is a 20% familial chance.

Children and Adolescents with Alopecia Areata

While in school, children and adolescents with AA may experience intolerance and rejection from peers. However, Favazza and Odom (1997) found that the more direct contact children have with others who appear different, the more tolerant they become toward those differences. Insights into self-esteem as well as coping with an obvious disability have been found by examining research on individuals with other visible disabilities such as an intellectual disability or cerebral palsy. Although AA in children and adolescents could be considered a form of physical impairment, teachers and staff should be informed that children with AA are not sick and their health is not compromised (Hunt & McHale, 2005b). According to NAAF (2011b), children with AA

describe teacher perceptions toward students with AA as (a) a healthy disease that the student cannot die from, (b) an allergic condition, and (c) they perceive children and adolescents as typical students. Further, teacher's comments indicate that they understand AA is an autoimmune condition, is not life threatening, nor does it limit a student's physical abilities. Individuals with AA can follow their dreams regardless of having the condition. One example is Charlie Villanueva, a National Basketball Association player with the Detroit Pistons, who also happens to have AA (Charlie Villanueva, from CBS News Sports, 2012). Another example, Kayla Martel has AA and was crowned Miss Delaware in 2010. She has stated, "confidence and compassion are the real makeup of a beautiful person" (Conley, 2011).

While most children and adolescents with AA do not receive special services, options do exist for school-based support. Some children and adolescents may seek school approval to wear hats or scarves in conjunction with providing documentation of a medical diagnosis. If this accommodation cannot be met, a 504 plan could be initiated. Yell (2006) states that, a 504 plan, which is part of the Rehabilitation Act of 1973, can be written to protect a child with a disability from being excluded from school programs and activities. This plan could give students with AA classroom accommodations or modifications such as the right to wear a hat in the classroom or a modified physical education class, especially on a windy day, when wearing a hat or hair piece for fear of exposure and embarrassment. An Individualized Education Program (IEP) could also be written under the category of Other Health Impairment (OHI) which is offered to students with chronic or acute health conditions that affect their school performance (Grice, 2002).

Grice also states that this plan should be determined on a case-by-case basis. When determining OHI eligibility, the effect of the disability on the child is first determined, then the effect on educational performance is analyzed (Grice, 2002). The definition of OHI is not clear on every disability and there seems to be some flexibility in securing services (Wodrich & Spencer, 2007). These authors also note that educators are capable of making appropriate classroom accommodations, however, they may have limited knowledge about a particular illness that needs attention. Therefore, a school's administration and staff need to be informed and given instruction on how to handle unusual illnesses or conditions that children may bring into their classrooms.

Interaction with peers is important for establishing social competence (Lee, Yoo, & Bak, 2003) and being able to connect with peers decreases feelings of loneliness and isolation. Dorries and Haller (2001) indicate that altered physical appearances can impede the acceptance of these young people with their peers. Children and adolescents with physical disabilities are often seen as outcasts, made to feel as if they do not exist, and are more vulnerable to being bullied (Bowman & Gordon, 2000; Llewellyn, 2000; Twyman et al., 2010). They are often excluded or just overlooked during extracurricular activities. An obvious physical difference can also negatively affect one's self-esteem, self-confidence, and feelings of self-worth (Bowman & Gordon, 2000), which can lead to stress and depression (Elliott, Frank, Corcoran, Beardon, & Byrd, 1990) and, in turn, lead to increased feelings of isolation and rejection. NAAF (2011a) encourages children and adolescents to report bullying and suggests that they (a) tell an adult, (b) travel in groups, or (c) stand up to the bully if it feels safe to do so. Schools may need to enact anti-

bullying campaigns to discourage such behavior. Children and adolescents with unusual physical features are often treated differently due to their atypical appearance. People might speak more slowly and increase their volume assuming that an altered physical appearance indicates a mental disability (Bowman & Gordon, 2000).

Favazza, Phillipsen, and Kukmar (2000) suggest that without support and encouragement, children without disabilities would not typically interact with their disabled peers. Lack of support can make meaningful connections between these two groups more difficult to attain. Although children and adolescents with AA are not disabled, they do possess an obvious physical difference. Classroom activities need to be planned so that all students have the opportunity to participate and contribute to the discussion (Diamond, 2001). Teachers need to act as role models in the classroom in the way they behave toward others, as well as how they communicate with others (Roberts & Lindsell, 1997). Roberts and Lindsell also found that teachers who actually taught students with physical disabilities were more positive in their attitudes than teachers with no such experience.

NAAF (2011b) describes problems faced by children and adolescents with AA. The children report: (a) being stared at and called bald, (b) being teased, (c) having to explain their condition to others, (d) confusing AA with cancer, (e) experiencing eye irritation due to lack of eyebrows and eyelashes, and (f) having to cover up in warm or cold weather to reduce exposure of their bald heads. The children commented that people also mistook their gender, which could compromise their identity. NAAF (2011a)

offers parents a School Packet that contains information for teachers. A DVD explaining what AA is can also be obtained for use in the classroom.

The identity of a child and adolescent can be defined by their outward appearance, accomplishments, and the many roles he/she play (e.g., sons/daughters, athlete, friend, musician). During the teen years, adolescents often crave more independence, but there may be a struggle between expressing oneself and family obligations (Bukatko, 2008). Children and adolescents with AA may experience an identity crisis. They may feel uncertain and confused about who they are and how they are perceived as an individual without hair. They may also have difficulty coping and may develop mood disorders like depression (Owens, 2002).

Children and adolescents are shown, through various media, how they should look to meet societal norms. According to Anderson and Skemp (2012), the media, peers, and family have an impact on how adolescents perceive themselves and can vary according to one's gender, age, race, culture, and maturity. Children and adolescents want to be a valued member of a peer group; however, low self-image, showing weakness, could contribute to victimization by peers (Egan & Perry, 1998). Children and adolescents with AA may be perceived as lacking confidence and could fall victim to an aggressor.

Treatments

Treatments vary according to the extent of the hair loss. Some treatments include (a) corticosteroid injections under the skin, (b) corticosteroid creams, (c) topical minoxidil (Rogaine), and (d) psoralen plus ultraviolet A light therapy (PUVA)

(Alkhalifah, 2013; McKillop, 2010). One therapy that has shown promise is injections of intralesional triamcinolone, which is a steroid drug that reduces inflammation (Springhouse Nurse's Drug Guide, 2004). However, this is only recommended for motivated adolescents because of some pain and discomfort associated with the injections (Hilton, 2001). Support groups are helpful to encourage individuals with this condition and reinforce the idea that these individuals are not alone (Prickitt, McMichael, Gallagher, Kalabokes, & Boeck, 2004).

The most common treatment for AA is the use of hairpieces (Hunt & McHale, 2005a). Individuals with AA understand that if they choose to go outside without a hairpiece or headpiece they may be attracting unwanted attention (Welsh & Guy, 2009). These authors cite an example of an individual with AA who chose to take off his hat on a hot day, but had an underlying feeling that people were thinking he was strange or odd. Many inaccurate assumptions have been made about people who have lost all of their hair, with the most obvious being cancer. Although hairpieces are generally used as a treatment for AA, they may not be the most comfortable solution.

Statement of the Problem

Our society tends to focus on physical appearances and individuals without hair often have a more difficult time blending in with others (Prickitt et al., 2004). A person's hair protects against the loss of body heat, shapes a person's body image, and affects an individual's social perceptions (Gallagher, 1997). Therefore, the loss of hair could affect an individual's self-perception, confidence, and self-worth. This study will investigate the social and emotional factors that affect children and adolescents with AA. The

teenage years can be particularly problematic as the individual becomes more self-conscious often analyzing and questioning themselves (NAAF, 2011a).

Although AA is not a debilitating physical disease, it presents a challenge for those affected because it can be psychologically disabling. Smith (2001) states, that nearly all individuals experiencing AA exhibited some psychiatric symptoms such as anxiety and depression. People with AA are often placed in a precarious situation, by trying to manage appearance in order to meet appropriate social situations by choosing hairpieces, hats, or scarves (Welch & Guy, 2009). Many people with AA feel alone and isolated from others because they feel there is no one like them with whom to relate, while others perceive their appearance negatively stating that they look pig-like due to lack of eyelashes and eyebrows (Hunt & McHale, 2005a). Olney-Friedrich (2001) and Pennington (1993) both stated that AA is a disfiguring condition. Many individuals with AA have shied away from social situations, while others have avoided work or school due to teasing. At the extreme end of the spectrum, some people with AA have considered suicide (Hunt & McHale, 2005a).

A combination of increased levels of anxiety and depression of children with AA were observed as compared to a control group in a study by Liakopoulou et al. (1997). This study also found that girls had more difficulty adjusting to their new self-image, and had problems with self-esteem, which led to symptoms of depression. Hair loss is particularly difficult for teens as they just want to blend with their peers leaving a feeling of loss and grief (Smith, 2001).

Coping is difficult because this disorder is unpredictable. The loss of hair can happen within a short period of time, or may take years. It may even cycle through active phases and remission (Hunt & McHale, 2005a). Individuals with AA are afraid of being rejected because of their visible difference (Welsh & Guy, 2009). This is a real fear because it is difficult to hide the fact that you are either losing your hair or that all of it has fallen out. Therefore, some people chose to avoid others in order to steer away from revealing or discussing their condition (McKillop, 2010). Parents of children with AA often feel guilty and powerless; they tend to project their own concerns and distress onto their children (Reeve, Savage, & Bernstein, 1996; Smith, 2001).

This medical condition has been studied and documented frequently in adults. However, there are limited studies and literature that address the factors that impact children and adolescents with AA (Elkin, Hilker, & Drabman, 2006). Therefore, this study explored the factors and coping strategies that affect children and adolescents as a result of having AA.

Rationale

The purpose of this study is to determine the factors that impact children and adolescents and the coping strategies they use to manage their AA. Poking fun at someone's unusual characteristic can be hurtful whether it is a congenital or environmentally induced disorder. Children and adolescents with AA look different from other children, and comparisons are often made to people with more severe health conditions (Welsh & Guy, 2009). Research on children and adolescents with AA is minimal and more information needs to be gathered as to how these individuals are

affected by this incurable condition and what coping strategies are useful and effective. Most articles focus on the psychological distresses of AA in both adults and children (Elkin et al., 2006; Kakourou et al., 2007; Kose, Sayar, & Ebrinc, 2000; Liakopoulou et al., 1997; Picardi & Abeni, 2001; Prickitt et al., 2004; Reeve et al., 1996; Smith, 2001).

Hunt and McHale (2005b) address the psychological impact of alopecia reporting that children with AA had psychological difficulties and showed more signs of anxiety, depression, and aggression. Young people had difficulty maintaining relationships and coping in school, which led to longer absences from school (Hunt & McHale, 2005a). In a study by Reeve et al. (1996), a positive link was noted between individuals with AA and psychological disabilities. The findings in several studies mentioned that parents tended to project their own anxiety to their child's condition (Elkin et al., 2006; Reeve et al., 1996; Smith, 2001).

Hunt and McHale (2005a) found that participants felt they needed to accommodate and adapt to their quickly changing appearance. Some experienced a frequent runny nose due to lack of nasal hair, unusually dry and sore eyes due to lack of eyelashes, and a loss of body heat from loss of scalp hair. Others felt distress by having to wear hair pieces in unpredictable weather conditions.

Children and adolescents diagnosed with AA are in a vulnerable position. They are old enough to understand that they look different from their peers, but are too young and possibly immature, to comprehend how to cope and manage the psychological impact of this condition. Therefore, coping strategies need to be identified and analyzed as to their effectiveness in supporting children and adolescents with AA.

Purpose of the Study

The overarching purpose of this study is to better understand the impact of AA on children and adolescents 10-19 years old. Therefore, the researcher examined factors that impact children and adolescents with AA and the strategies they use to cope with this condition. AA has both physical implications and psychological considerations. Understanding how these individuals view themselves and the strategies they use to handle their AA on a daily basis was the focus of this investigation. Contributing to the limited research in this area could lead to insight into areas of intervention, effective coping strategies, behavioral support, and strategies to better support the psychological well-being of children and adolescents with AA.

Research Questions

Seven research questions will guide the study:

1. What are the factors that impact children and adolescents with AA?
2. What types of coping strategies are used by children and adolescents with AA?
3. How do the impact factors differ by group (e.g., age, gender, onset, and duration)?
4. How do the types of coping strategies used differ by group (e.g., age, gender, onset, and duration)?
5. Which individual impact items have the greatest and least influence on children and adolescents with AA?
6. Which types of coping strategies are used most and least frequently by children and adolescents with AA?

7. How do children and adolescents describe the experience of having AA over time?

Significance of the Study

AA is unpredictable and incurable; it can be challenging to any individual who is affected. Children and adolescents are more vulnerable due to their age and understanding of this condition. AA is the most common hair loss disorder in children (Hilton, 2001) and the social stigma associated with this condition can also be psychologically damaging (Hunt & McHale, 2005a). An individual's personal identity, self-esteem, and well-being are at risk (Hunt & McHale, 2005b). Harrison and Sinclair (2003) suggest that children with AA are more likely to be teased at school, which could lead to depression and anxiety. Therefore, gaining a better understanding of the factors that impact children and adolescents with AA is essential. In addition to understanding the factors that impact children and adolescents, it is also important to know how to deal with this condition on a daily basis.

Discovering effective and simple coping strategies for children and adolescents with AA could improve their quality of life. Osman, Mufaddel, Almugaddam, and Augusterfer (2011) comment that modern society expects individuals to keep up an attractive physical appearance and by doing so, they will live a more fulfilled and positive life. Various treatments have been used to maintain current hair status or replenish lost hair. However, these treatments have been disappointing in outcomes, and are associated with unpleasant side effects (Mukherjee, Burkhart, & Morrell, 2009).

Coping, which is the ability “to deal effectively with and handle stresses” (Taber’s Cyclopedic Medical Dictionary, 2013, p. 564) can take many forms including: (a) medicinal treatments, (b) alternative treatments, (c) cosmetic cover-up, (d) community and outside support, (e) communication/technology, and (g) family support. As a result of this study, the researcher describes the coping strategies children and adolescents view as being valuable in managing their AA. The descriptions of these strategies include the varied perspectives between children and adolescents as the course of AA is unpredictable and individualized.

Definition of Terms

Alopecia Areata. Absence or loss of hair on the head (Taber’s Cyclopedic Medical Dictionary, 2013, p. 88). Alopecia areata (AA) is an autoimmune disease that results in the loss of hair on the scalp and elsewhere on the body and does not discriminate between genders, age, or race (Papadopoulos et al., 2000). There are three types of AA: Patchy alopecia areata (AP) involves the loss of hair, usually in patches on the scalp; alopecia totalis (AT) is when the entire scalp is hairless, but hair on other parts of the body still exist; and alopecia universalis (AU) involves the loss of all body hair. Individuals are more likely to respond to treatment with AP than with AT or AU (Hunt & McHale, 2005a).

Children and adolescents. For the purpose of this study, a child is defined as a young person of ages 10, 11, or 12. An adolescent is defined as a young man or woman who is not fully grown; from the beginning of puberty until maturity (Taber’s Cyclopedic Medical Dictionary, 2013, p. 54).

Duration. Duration is the length of time a participant has had AA. It was divided into two groups based on a midpoint split of the data. For the purposes of this study, short duration includes participants having AA for 1 through 6 years, and long duration included participants having AA for 7 through 17 years.

Assumptions

Several assumptions have been made regarding children and adolescents with AA. It is assumed that the survey participants were truthful in their responses and accurately reported the requested information. Although it is impossible to monitor, the researcher trusts that the younger children in the study answered the questions without undue prompts from their parents or friends. The researcher also presumes that some of the responses of the participants during the follow-up interviews were not unduly influenced by the researcher as she also has AA, which was clearly visible to the participants.

This investigation is exploring an area that has limited research with most of the existing research focusing on the reactions of adults rather than children and adolescents. The researcher assumed that the experiences of the participants would be similar to the experiences noted in the existing literature base. For instance, prior research found AA to be psychologically challenging inferring that the experience may be difficult and depressing for children and adolescents. In addition, the researcher may have subconsciously assumed that the experience of her participants would be similar to her own since she has had AA for 25 years and has experienced some life challenges as a

result. Therefore, comparing the results from the current study and the existing literature was difficult and required safeguards to manage the potential bias of the researcher.

The researcher also assumed that the survey would produce a high number of respondents due to the number of NAAF members. Halbesleben and Whitman (2013), state that response rates can pose problems even though they are thought to be the measure of the quality of a survey. A high response rate does not necessarily secure quality results that can be generalized to the entire population (Baines, Partin, Davern, & Rockwood, 2007). Strategies to encourage responses were used such as sending a follow-up request one week after the initial survey request and another two weeks after the initial survey. In order to reduce nonresponse, Kreuter (2013) suggests limiting the number of questions asked of respondents. Many people perceive surveys as a burden and are then unwilling to participate. Massey (2013) also adds that collecting data via a survey is threatened by potential respondents who do not understand and appreciate their importance.

Delimitations

The literature review uncovered coping strategies used by adults that the researcher chose not to include when creating the survey instrument as these topics were viewed as unsuitable for children and adolescents. These undesirable strategies included (a) drugs (overuse or illicit), (b) alcohol, (c) isolation, (d) rejection of previous recreational and social engagements, and (e) suicide attempts. Not only did the researcher want to avoid mentioning these coping choices in case they could be misinterpreted as viable options, but the university institutional review board views

children as a vulnerable population with whom discussion of such dangerous behavioral topics may create an adverse effect.

The proposed study is limited to children and adolescents 10 through 19 years of age. A younger population could have difficulty addressing the questions adequately in the survey or during an interview without adult prompting. Participants older than 19 would be considered adults and would not fit the proposed age group of children and adolescents set forth for the study.

The survey was limited to members of NAAF with access to electronic resources (e.g., e-mail, Facebook, Twitter). The study excluded members of NAAF without electronic capabilities. The survey was electronically sent to members of the NAAF in the United States. Other NAAF affiliated locations were excluded. Additional children, adolescents, and families who were not members of this organization were also eligible if they could access the survey electronically and resided in the United States.

Summary

Being hairless in a society that places emphasis on appearances and societal protocol proves to be challenging for many individuals, especially children and adolescents with AA. Treatments for this condition are varied and often do not produce the desired results. Coping measures can be effective, but do not completely safeguard against circumstances beyond one's control. The focus of this investigation will be not only about how children and adolescents view themselves, but how this condition affects them daily and their ability to cope with their altered physical appearance.

2. LITERATURE REVIEW

This chapter presents a summary of the literature. There have been different approaches to the study of AA. Medical research on AA has focused primarily on how the body reacts to this condition, variations of alopecia, other disease processes that are involved, treatments, and the psychological impact of this condition. While this review includes some of this information for clarification of AA, the social and emotional impact of AA was examined in depth. This study intends to concentrate on the factors that impact children and adolescents and the strategies they use to manage their condition. AA not only affects how an individual is perceived but could affect how a person functions on a daily basis. Hunt and McHale (2005b) contend that AA is a form of disfigurement that can affect a person's self-identity. Society places emphasis on appearance and the lack of the attractiveness that is associated with hair loss can lead to a negative self-impression (Matzer, Egger, & Kopera, 2011; Welsh & Guy, 2009).

The review of literature indicates that there have been limited studies conducted solely on children with AA regarding impact factors and coping strategies. Therefore, this review includes a comprehensive search of the literature on children and adolescents with AA. Few studies have been completed that include children and adolescents exclusively, so additional studies with adults were included to fill gaps of information. The computer-assisted searches included the following databases: (a) ERIC,

(b) PsycINFO, (c) Medline, (d) Web of Knowledge, (e) Cochrane Library, and (f) Dissertation Abstracts. Keywords used in the search included: alopecia areata, hair loss, self-esteem, children and adolescents, psychological effects, coping strategies, treatments, and support. Articles, not available through the databases were obtained through George Mason University's interlibrary loan service.

Characteristics of Alopecia Areata

AA is a challenging disorder psychologically, especially when hair is lost not only on the head, but also loss of eyelashes, eyebrows, and nose and ear hair (McKillop, 2010). AA is a benign condition, but runs an unpredictable course, which can be frustrating to the individual with the AA (Pennington, 1993). Individuals can start out with patchy alopecia (AP) and progress to alopecia totalis (AT) and eventually alopecia universalis (AU), the most extreme condition in which a person loses all body hair (McKillop, 2010). In addition, because of the unpredictable nature of this disease, individuals can alternate between diagnoses of AP, AT, or AU until the process becomes inactive. The symptoms do not have a specified course, and may disappear, or may develop into AT or AU. However, spontaneous hair growth can happen, although it may only be temporary (Price & Khoury, 1991). Bedocs and Bruckner (2008) found that hair may regrow within a year. In addition, prognosis of hair regeneration is poor if more than 50% of the scalp is affected (Hilton, 2001). However, because this condition is highly irregular, a person may relapse many times over his/her lifetime. Similar information was also found in Hunt and McHale (2005b). The cycle of the disease alternates between actively losing hair to complete remission with a good possibility that

this cycle may repeat itself. Further, if hair does return, it may not be the same color or texture that it was originally. There is also a tendency for the hair loss to be confined to pigmented hair (MacLean & Tidman, 2013). Liakopoulou et al. (1997) suggests that the earlier a child is diagnosed with AA, the prospects for a recovery or reversal is more likely. However, Tan, Tay, and Giam, (2002) found that the earlier the onset of AA and the more extensive the hair loss, the less favorable treatment outcome. The unpredictability of this condition makes it difficult to treat both medically and psychologically.

AA can occur any time within a person's life time (MacLean & Tidman, 2013). It does not discriminate between age groups, gender, or race (Papadopoulos et al., 2000). In an update by Kos and Conlon (2009) the onset of AA is commonly seen in children and adolescents. In addition to recognizing and treating children with AA, Hilton (2001) also noted that AA is the most common hair loss disorder in children and it usually occurs in school-aged children, which can be a challenging and stressful time period for children and adolescents (Owens, 2002). Safavi et al. (1995) conducted a study in which the age range at the time of initial diagnosis was between 1 year and 91 years. This study followed residents in one county in Minnesota over 15 years. They found that AA was a common occurrence, was seen at all ages, was not brought on by seasonal changes, and that compiling a family history would give a more complete picture of this condition. Although it is rare, infants are sometimes born with AA (Bardazzi, Neri, Raone, & Patrizi, 1999). Nanda, Al-Fouzan, and Al-Hasawi (2002) conducted a study in which the youngest infant in their study was 1 month old. They studied the causes and patterns of

AA on children and found no relationship between family history and age of onset to the severity of the condition. However, MacLean and Tidman (2013) suggest that there is a family history in 20% of cases.

An initial test a dermatologist conducts is the pull test. It is used to determine the vulnerability of the hairs. The hair is pulled gently between the thumb and fingers over several different areas of the scalp. Excessive shedding of the hair is indicated if more than two to six hairs are pulled out at one time. These hairs are then examined under a microscope (Hilton, 2001; MacLean & Tidman, 2013; Tosti & Gray, 2007); and if a particular diagnosis is unclear, blood tests and biopsies are then conducted.

Nail pitting, longitudinal ridging of fingernails and thin and brittle fingernails are also common characteristics of AA (Gilhar, Etzioni, & Paus, 2012; Papadopoulos, Schwartz, & Janniger, 2000). In addition, nail pitting is found in approximately 10% to 20% of patients (Hilton, 2001). Thomas and Kadyan (2008) concur that 15% of participants had some type of nail involvement like pitting, ridging, or discoloration.

Alopecia Areata and the Immune System

In a number of studies, emotional and physical life stresses appear to have a strong connection as the trigger for developing AA (Hunt & McHale, 2005a; Hunt & McHale, 2005b; Kakourou et al., 2007; Matzer, Egger, & Kopera, 2011; McKillop, 2010; Paga et al., 1992; Pennington, 1992; Reeve et al., 1996). Emotional or physical stress examples given were (a) a death in the family, (b) beginning school, (c) birth of a sibling, (d) end of a relationship, (e) an operation, or (f) public speaking (Kakourou et al., 2007; Paga et al., 1992). However, Osman et al. (2011) implies that stress can exacerbate

medical conditions, including the skin. Thomas and Kadyan (2008) suggest that stress could be associated with AA. However, they also find that the pathology could be linked genetically or by way of an immune or autoimmune reaction. In their study on children, Diaz-Atienza and Gurpegui (2011) noted a relationship between developing AA and stressful life events.

Bartrop et al. (1977) studied bereaved spouses and concluded that psychological stress resulted in an abnormal immune function. Tecoma and Huey (1985) also noted that stress has been linked to deficiencies in the immune system. Perini (1984) studied 108 patients, 48 with AA, 30 with common baldness, and 30 with a fungal infection. Participants were interviewed and given Paykel's Recent Life Events scale. Life events were compared and participants with AA experienced more negative impacts from life events such as death, divorce, birth of a child, and marriage than the other groups. They also found some evidence connecting AA with an autoimmune disorder. De Weert, Temmermann, and Kint (1984) conducted a study to examine a relationship between autoimmunity and AA. Their results, however, were inconclusive. They did find that AT was more prevalent in children, and when hair loss becomes more extensive, successful treatment is less likely. They also noted chronic stress in 70% of individuals with AA, but were unable to verify that the cause was AA itself or just a result of societal pressures.

Authors of articles diagnosing and treating hair loss, (Hilton, 2001; Kakourou et al., 2007; Mounsey & Reed, 2009; Papadopoulos, Schwartz, & Janniger, 2000) state that AA is associated with other autoimmune diseases such as: (a) vitiligo (causes the skin to

lighten), (b) diabetes, (c) thyroid disease, (d) celiac disease, (e) psoriasis, (f) rheumatoid arthritis, and (g) lupus. Kakourou et al. (2007) found a connection between familial autoimmune diseases and children with AA and contend that symptoms of AA and vitiligo have preceded the development of thyroid disease and suggest that thyroid screening was important in all children with AA. Hawryluk and English (2009) concur that the thyroid should be tested on all patients. Thomas and Kadyan (2008) add that autoimmune disorders are common with AA, with thyroid disease being the most common.

Variations of Alopecia

Common variations of AA include (a) tinea capitis (scaly scalp with fungus), (b) traction alopecia (patchy hair loss due to the pulling of hair like tight braids), (c) trichotillomania (compulsive disorder of hair plucking), (d) cicatricial alopecia (scarring due to destruction of hair follicles by an autoimmune disease), (e) telogen effluvium (hair loss due to injury, crash diet, or giving birth), and (f) anagen effluvium (chemically induced hair loss, like chemotherapy) (MacLean & Tidman. 2013; Mounsey & Reed, 2009; Nield, Keri, & Kamat , 2006). Nield et al. (2006) also emphasize that a complete history be taken with follow-up cultures and blood work, if needed, to rule out other diseases. Bedocs and Bruckner (2008), concur that a background history is important and that professionals are looking for onset and duration of hair loss, as well as hair care practices, overall health, current medications that are being taken, and symptoms of thyroid disease.

Across Genders

Hair expresses a person's individuality, and losing hair can affect a person psychologically (Kranz, 2011). Lack of hair can also have an effect on a person's self-esteem due to teasing and a sense of negative self-worth (Cash, 1999). This perception was also noted in Cash (1990) as females judged balding men as unattractive and not being as successful as men with hair. This change in appearance has led to behaviors of concealment, frequency in checking appearance and seeking out reassurance. Most of the research has concluded that women have greater difficulty with hair loss than men due to societal pressures to be attractive (Tucker, 2012). However, the majority of participants in the studies have been women with the exception of a study by Al-Mutairi and Eldin (2011) where males outnumbered females by 1.86:1. They also reported that boys had a higher incidence of a more severe form of AA than girls. This appears to be due to the higher number of males in their study.

Gallagher (1997) completed an exploratory descriptive study on 10 women prior to and at the time of hair loss associated with chemotherapy. Loss of hair in women is a social and cosmetic liability. Many anticipated that they would look ugly, and feel sad, and threatened. Most of the women tried hair saving coping strategies such as pressing down on their scalp, and not washing or brushing their hair. They knew the inevitable, but were still surprised when hair fell out. Many wore a wig and considered it a prop. A number of women felt that their negativity toward their hair loss was shallow and conceited.

In the Liakopoulou et al. (1997) study the girls also appeared to suffer more from self-image issues. These participants were also more depressed and withdrawn. Pennington (1993) found that even though females were predicted to have a lower self-esteem, it was not supported by the data. The reason given was that females were likely to use cosmetics (hair pieces and makeup) to cover up their impaired appearance. Balding women viewed their quality of life negatively and had difficulty in day to day activities. Many did not want to be seen in public bald, and some had placed a limit on socialization while others tried to avoid work (Hunt & McHale, 2005a; Van Der Donk, Huntfeld, Passchier, Knecht-Junk, & Nieboer, 1994). Some perceived that they were being treated prejudicially even when they were not. Heaven and Ciarrochi (2008) observed that girls overall have a lower self-esteem than boys. Females have been stereotyped as staying at home to nurture the children while being encouraged to pursue traditional male dominated professions. These conflicting roles could explain why females struggle with self-esteem issues (Tenenbaum & Leaper, 2003).

Seven women and four men were recruited for a study by Welsh and Guy (2009) in order to examine their adjustment and coping strategies with AA. Interviews were conducted via audio tape. Initially, all participants tried to hide their bald patches. They used scarves, hats, headbands, and sprays. Some individuals rejected wigs because it meant a long term prognosis. Women had a more difficult time adjusting to their hair loss and a hairpiece seemed to be the only viable option. In fact, all women in this study purchased a hair piece in order to take charge of their appearance. Positive comments

that women made were that they were able to get ready for an outing quickly and were able to change their appearance often.

Hair has an overwhelming impact on a women's self-image according to Freedman (1994) because of numerous cultural implications such as a person's religion, class, or occupation. They found that hair loss was seen as more traumatic than losing a breast from cancer and that some patients would rather lose a body part such as a breast than lose their hair. Hair was seen as a characteristic that gives a person their identity and losing hair can be perceived as a loss of self. One participant stated, "Who will I be without hair?" (p. 337).

Males tend to be more successful at coping than females because bald men are seen as more acceptable in society (Hunt & McHale, 2005a) and men are less likely to cover bald patches (Vandegrift, 1994). Cash, Price, and Savin (1993), suggest that women place more emphasis on their looks than men in order to look more attractive and normal. The visibly altered image tended to cause more distress in women. On the other hand, Cash (2009), completed a study on the attitudes and behaviors of men with male pattern hair loss and found that they also experienced negative psychological effects from losing their hair. Tan, Tay, Goh, and Giam (2002) reported that males with extensive hair loss had more severe psychological effects including depression and feelings of helplessness in dealing with their hair loss. These researchers commented that these feelings could be culturally linked. Asian men perceived themselves as being strong and confident and were less likely to seek outside help. Welsh and Guy (2009) noted in their study that even though loss of hair in male participants was distressing, they were less

likely to attend support group meetings as a coping strategy. These participants chose to take control by shaving their heads, which is commonly seen in today's society (Cash, 1999; Welsh & Guy, 2009).

Pennington (1993) noted that self-esteem of young males versus older males showed significance. Younger men revealed lower self-esteem than older men, as older men were more prepared for coping with the aging process, which included premature balding. The data on depression resulted in no significant difference, although younger men were slightly more depressed than older males and younger females. Her hypothesis also predicted that younger males would have higher stress levels than older males. The opposite was found. Older males had higher stress levels due to the fact that they were not only dealing with a disfiguring condition, but also with mid-life stressors. Another hypothesis was that those living with AA for a longer period of time would have lower levels of stress and depression while the self-esteem levels would rise. This hypothesis was also not supported. It was assumed that after living with this condition one would learn adaptive coping skills. The participants in the groups were recruited from support groups that could have possibly alleviated some of the symptoms of depression, stress, and lowered self-esteem. Pennington also found that, overall, younger males appeared to have more difficulty managing their AA than females.

Potential Impact Factors

Much of the research on children and adolescents with AA has been devoted to the effects of stress, depression, and treatment. However, AA not only affects individuals psychologically, it also impacts the social and emotional life of patients (Al-Mutairi &

Eldin, 2011), which causes them to change their social life, their hair style or cover, and possibly the clothes they wear. Ito (2011) notes, although AA is not life-threatening, it can decrease quality of one's life. Children and adolescent's self-esteem is also in question due to their altered appearance and questions regarding their condition (Beard, 1986; Goddard, 2010). Raquepaw (1990) found that individuals with AA were more depressed and anxious than individuals in the control group and that they had a poorer self-esteem. The emotions of adolescents are inconsistent and unpredictable, and how they learn to cope with these emotions will have an effect on their psychological health (Bukatko, 2008). Maintaining a positive self-image and managing AA may be difficult, as the diagnosis and progression is individualized and the course of this condition varies across ages and genders. Daily stressors for children and adolescents with chronic conditions have included: (a) missing school, (b) falling behind in school work, (c) changes in appearance, and (d) not being able to do the things they were used to doing (Compas, Jaser, Dunn, & Rodriguez, 2012).

A positive self-esteem is a valuable trait in the development of children and adolescents and can promote confidence, independence, and a sense of self-worth. There are many factors that can influence how children and adolescents assess their self-esteem including, but not limited to (a) academics, (b) athleticism, (c) appearance, and (d) parent, peer, and teacher perception. A lowered self-esteem could lead to depression, anxiety and difficulties in school and during social interactions (Bukatko, 2008). This author also states that children and adolescents tend to be particularly concerned about their physical

appearance and that dissatisfaction with their looks may lead to lower self-esteem. A child's self-esteem is also linked to parent support and acceptance (Buri, 1989).

Personal appearance is an important characteristic as it is obvious to others while socially interacting (Pennington, 1993). While maintaining an attractive physical appearance is practiced by both genders (Osman, Mufaddel, Almugaddam, & Augusterfer, 2011) physically attractive people are more likely to have positive life experiences. Prickitt, McMichael, Gallagher, Kalabokes, and Boeck (2004) also suggest that society focuses on physical appearances, which can be psychologically difficult for individuals without hair trying to conform. Beard (1986) adds that individuals with AA can be made to feel inadequate compared to others and that they may be seen as outcasts. The loss of hair could be directly related to lower self-esteem and anxiety (Beard, 1986; Dinh, & Sinclair, 2007; Goddard, 2011). Children with AA can be affected negatively and are likely to be ridiculed at school which can lead to anxiety and depression (Harrison & Sinclair, 2003). Adolescents who feel high stress levels are more likely to experience negative emotions (Bukatko, 2008).

Stress and anxiety has been associated as an underlying cause of AA, however, there has been a lack of definitive data. In Colon, Popkin, Callies, Dessert, and Hordinsky (1991), stress was assessed, via a structured psychiatric interview. They found that 39% of their participants felt stressed regarding their AA. However, Kakourou et al. (2007) found that emotional or physical stress was seen as a precipitating factor in about 10% of their cases. Kyser (1993) and Pennington (1993) both stated that acute stress or trauma could be a precipitating cause of AA. Stress is difficult to measure

and record and individuals react to and handle stress differently. Monselise et al. (2013) conducted a study on the relationship between AA and emotional intelligence. They note that stress may not promote the onset of AA, but may be linked to altered stress responses. Pennington (1993) contended that individuals with AA reported greater stress levels than the control group which had experienced more positive life experiences than those with AA. Kyser (1993) also noted that 56% of her participants did not think that life stresses contributed to their hair loss. Monselise et al. (2013), suggest that sudden hair loss can be devastating and can be connected to emotional pain.

In a study by Matzer et al. (2011), people with AA expressed higher stress levels prior to the onset of AA. Approximately 66% thought that stress had something to do with the course of this disease. Eighty-four percent of the participants in this study stated that emotional stress including anxiety, depression, and shock was initially felt at the beginning of their hair loss. Re-growth of hair seemed to reduce emotional distress. These authors also noted that 80% perceived their body image as unattractive and vulnerable and expressed social discomfort in their families and partnerships, as well as negative reactions by others. Women especially felt more stressed than men because of physical unattractiveness. Participant's attitudes toward themselves became more positive when AA symptoms were getting better as opposed to those who were either not growing hair or losing more hair. Some felt discrimination in the job market due to negative verbal comments about their appearance. Changes in a person's body image and physical appearance seems to be more distressing than pain or other body symptoms. Invernizzi (1987) utilized Paykel's scale on 14 patients with AA and 43 control

participants without the dermatological condition. Their results revealed that individuals with AA experienced more stressful life events than the control group and confirmed a strong association between stressful life events and AA. They also had a higher incidence of depression than the control.

Hunt and McHale (2005a) conducted two studies in their research on AA. The first study examined the psychological impact of AA on 162 individuals between the ages of 12 and 93. They were asked to provide written commentary about their experiences with AA. The participants with limited AA experienced more severe symptoms than those with more extensive hair loss. Approximately 33% were children or adolescents. The second study focused on interviewing via e-mail, 34 participants, only four of which were children, with follow-up questions. The authors indicated that the parents of the children contributed during the interview. It is not known to what extent the parents coached or answered for their children and, therefore, biased the results. Participants in the Hunt and McHale (2005a) study commented about how distressing AA is in relation to physical appearance. Many had feelings of loneliness, loss of confidence, and shame. They also had difficulty adapting to their new identity. These participants were also distressed to learn that there is no cure for AA. Some tried alternative, costly therapies but ended up feeling hopeless.

Children and adolescents gradually develop their identity over time. They can be influenced by family members, peers, and the media to look a certain way in order to meet societal norms (Anderson & Skemp, 2012). Developing adolescents take their physical appearance seriously, begin establishing a sense of identity, and are developing

socially (American Psychological Association, 2002). Children and adolescents with AA may experience an identity crisis. Anderson and Skemp (2012), state that one's body image is connected to self-esteem. The loss of hair may be confusing and the ability to cope may be compromised, which may lead to self-esteem issues. Children and adolescents want to be accepted by their peer groups; however, lack of confidence and perceived vulnerability, could lead to victimization by peers (Egan & Perry, 1998). According to Dawkins (1996), bullying can be related to an individual's special need or disability. Many of these children and adolescents are ostracized and excluded from extracurricular activities (Twyman et al. 2010).

Young people today are more tolerant regarding social issues than any other generation (The Pew Research Center, 2007). They also use the latest technology to stay close to friends and family, as well as forming new relationships. They rely on their families for advice and assistance.

Egan and Perry (1998) found that children ages 11-13 with low self-esteem fall victim to peer abuse. This victimization resulted from the fact that these children were unable to assert themselves during conflicts and lacked a social network of friends for support. In addition, some children actively sought out their oppressor for social interaction. In another study, Hodges, Malone, and Perry (1997) found that victimized children often befriended other victimized children. However, if these friends were perceived as being weak and unable to provide protection, the risk of victimization would still be present. These children were also more prone to depression, anxiety and low self-esteem.

Koszalinski and Williams (2012) examined the concept of embodying identity, which is how individuals change the perception of themselves in order to reconcile physical or body alterations. Their case study involved a mother of four with a rare brain tumor. The tumor was successfully removed; however, this woman's underlying fear was going bald from chemotherapy. She had difficulty accepting her altered appearance. When changes like this happen to individuals, they question their identity and need to work reconciling with their new appearance. Feelings of insecurity due to lack of confidence could surface that may lead to psychological issues of depression and anxiety.

Liakopoulou et al. (1997) found that children with AA had more difficulty psychologically than those without AA. Their study analyzed 33 children with AA, 9 to 11 years of age, used four scales that measured behaviors as perceived by the parents: (a) an anxiety scale, (b) depression scale, and (c) a life events scale. An additional 16 children who had AA for less than a year were examined for stressful life events only. A control group consisted of 30 children, 8 to 13 years of age, and 16 preschool children with mean age of 4.2 years. Their findings revealed that all 33 children analyzed had problems behaviorally, as well as psychological problems of anxiety, depression, and withdrawal. Embarrassment and sadness were prevalent reactions. Problems with socialization were also present. These problems sometimes led to unacceptable behaviors.

Aggressive behaviors were observed in children with AA and were thought to be linked as a reaction to teasing (Liakopoulou et al., 1997). According to Beard (1986), teens seem to have a more difficult time adjusting to their hair loss as their appearance and individuality is closely examined by others. Grades and ability to concentrate in

school are also at risk as some of these students are harassed and intimidated. Hunt and McHale (2005b) explored the psychological impact of alopecia remarking that children with AA had psychological difficulties and showed more signs of anxiety, depression, and aggression. The onset of AA at an earlier age could result in isolationist behaviors, or behaviors that could be potentially harmful, risky, or dangerous like substance abuse (Colon et al., 1991).

Several studies have compared AA to loss of hair from chemotherapy (Gallagher, 1997; Munstedt, Manthey, Sachsse, & Vahrson, 1997; Raquepaw, 1990). Children and adolescents are often mistakenly targeted as having cancer (Welsh & Guy, 2009). Chemotherapy is a life-saving treatment, and hair loss is usually temporary. In contrast, AA is an autoimmune condition that affects healthy individuals and could last a life time. Cancer treatments can change a young person's body image and sense of personal worth as can AA. Some cancer patients have been able to accept their hair loss from chemotherapy because it is only temporary and hair options are readily accessible (Munstedt, Manthey, Sachsse, & Vahrson, 1997). Some individuals have commented that losing hair was the most devastating side effect of chemotherapy due to the fact that it is such a visible change (Gallagher, 1997; Manchester, 1981; Munstedt et al., 1997). So traumatic in fact, that, a patient stated, "I'd rather die than lose my hair" (Vandergrift, 1994, p. 79). Individuals diagnosed with cancer are able to anticipate the possibility of hair loss and are able to explore wig options and support groups ahead of time (Borsellino & Young, 2011; Munstedt et al., 1997), whereas, individuals with AA are often surprised by the loss of hair and may have to consider a wide range of options

during their lifetime due to the ever changing course of AA. These findings suggest that there is a concern and a need for coping strategies for individuals who have lost all of their hair to restore their psychological well-being.

Twenty years ago, three dissertations were written on AA from a psychology point of view. The three studies focused on the psychological effects of alopecia on individuals between the ages of 16 and 79. The first, written by Raquepaw (1990) investigated the psychological and behavioral effects of alopecia areata. The second, written by Pennington (1993) examined the impact of alopecia on an individual's self-esteem, depression, and stress. The third, written by Kyser (1993) studied the coping styles and adjustment factors associated with alopecia areata. The female participants outnumbered the male participants in all three studies, which may indicate a need for further research on the impact alopecia areata has on females. It could also suggest that women had a vested interest in getting answers, support, or connections by participating in a study that directly affected them. They all used four instruments in their studies but only one inventory was common to both Pennington (1993) and Raquepaw (1990), the Beck Depression Inventory (BDI). All three researchers emphasized the need for a psychological referral after a diagnosis of AA. However, referrals were rarely given (Raquepaw, 1990), or only 23% of patients sought out this type of therapy (Kyser, 1993). Implications of these dated findings confirm the need for up-to-date studies on AA, especially on children and adolescents.

Raquepaw's (1990) dissertation focused on the psychological and behavioral effects of AA. She found that depression is linked to individuals with AA and that

children often find themselves in precarious situations due to bullying or just participating in outside activities. These situations can affect the types of coping skills one uses to deal with their AA. Several of her hypotheses were of interest for this present study. She hypothesized that the age of onset and severity of an individual's AA could predict levels of depression, anxiety, or self-esteem. However, no relationships were found. She also hypothesized that AA would have a greater psychological impact on the lives of adolescents than on adults. Again, the data did not support this hypothesis due to the fact that of the 106 participants, only four were adolescents. She also proposed that women with AA would be affected to a greater extent than men on measures of depression, anxiety, self-concept, and social behaviors. Once again, there was not a significant relationship as the data were skewed because the study participants included 89 women and only 16 men. Eighty-one percent of the participants stated that they wore wigs or another form of camouflage, although gender was not stated. The older participants and more depressed participants tended to wear wigs more often, but there was no indication as to the gender of these participants. Her findings confirmed other reports in the literature: (a) individuals with AA were more depressed than those in control groups and (b) support groups had a more positive effect on self-esteem. She did comment that dermatologists need to be more aware of psychological issues with their patients. Dermatologists only referred 12.5% of their patients to seek professional counseling, while 40% would have liked such a referral.

Pennington (1993) wrote a dissertation on how AA affects age and gender in the areas of self-esteem, depression, and stress. She had two groups of adults ages 18 to 65.

The research group included 41 females and 21 males with AA, while the control group included 20 females and 20 males. Again, the females in this study also outnumbered males. According to the U.S. Census Bureau, females outnumbered males by 50.8 to 49.2 (U.S. Census Bureau, 2012). The researcher contended that people who are stigmatized due to a disorder are often shunned by society which could lead to lowered self-esteem and depression. Society judges people who have an impaired appearance and becomes suspicious, often rejecting those different from the norm. This author considered AA to be a disfiguring disease. Also, many people confused a balding person for one who had gone through chemotherapy. This misconception was also noted by McKillop (2010) and Welsh and Guy (2009).

Pennington (1993) noted that AA is harmless to the health of an individual, but can be frustrating due to its unpredictable course. Dermatologists offer medical options, which are often unpredictable with disappointing results. However, the psychological issues are often not addressed the first year of acquiring AA, which is often the most difficult and thoughts of suicide are common. She also maintained that, early psychological interventions need to take place for individuals with AA, which reiterates the findings of Raquepaw (1990). Messenger, McKillop, Farrant, McDonagh, & Sladden (2012) add that while AA has no direct impact on an individual's general health, psychological effects may have an impact on health.

Pennington (1993) concluded that the self-report measures were not supervised and no support was given to clarify directions or alleviate anxiety. Finally, the participants were recruited from support groups or outpatient dermatology clinics where

they received support and may have gained greater coping abilities than those who did not attend support groups.

Kyser (1993) wrote her dissertation on AA focusing on the coping styles and adjustment of adult men and women with AP, AT, and AU. The ages ranged from 19 to 60 years. However, the breakdown of the ages was not mentioned. She suggested that a person's overall confidence and attitude was associated with their coping strategies. The common medical treatments used were similar to the findings in other studies and were considered disappointing as some of the treatments were worse than losing hair. For example, Dinitrochlorobenzene (DNCB) caused severe itching and swelling, and topical steroids and monoxidil would need to be used for a prolonged period of time. She also found that individuals who tended to blame themselves for their condition usually viewed themselves negatively, which resulted in lower self-esteem and depression. Some used "wishful thinking" as a strategy, which led to a poorer psychosocial adjustment.

The scales used in Kyser's (1993) study focused on coping, adjustment to an illness, and control and prediction of their condition. The coping scale measured problem focused coping versus wishful thinking, social avoidance, support measures, and self-blame. Individuals experiencing a shorter duration of AA sought out social support less frequently than individuals experiencing AT or AU (Kyser, 1993). This is possibly due to the fact that there is greater or more extensive hair loss with AT and AU. Although, the longer an individual lived with AA, the more accepting they were of their appearance. However, 56% did not think stress was a trigger. Fifty-seven percent of participants

thought that genetics played a role in their hair loss, while 22% thought it was divine will, and another 67% thought the cause to still be unknown.

Three quarters of the individuals in this study were able to overcome any problems AA had caused them by seeking out support. Children and adolescents may not be as adept in their seeking out support strategies and may need adult intervention. The coping strategies of the individuals in the Kyser (1993) study changed with the course of the disease. Many individuals coped by staying involved with friends and support groups. Fifty-nine percent stated that parents were actively involved in helping them cope. The coping strategies in this research were limited to problem and emotion-focused coping (e.g., wishful-thinking, avoidance, self-blame), which only touches the surface of coping strategies when trying to manage AA.

In the Hunt and McHale (2005a) study of 196 participants between the ages of 12 and 93 were studied to examine personal, social, and medical affects AA had on the participants. One of their first discoveries was that the participants needed to quickly adapt to their changing physiology. For example, many had runny noses due to lack of nasal hair, eyes were dry and sore due to lack of eyelashes, and they were also more sensitive to temperature changes from loss of scalp hair.

Another study involving children by Reeve, Savage, and Bernstein (1996) examined 12 children with AA between the ages of 6 and 17 to confirm their psychiatric diagnoses. This was completed through Psychiatric interviews, anxiety scales, depression scales, life event checklist, environment scale, and a behavior checklist. Scores were calculated and they found a positive link between individuals with AA and

psychological disabilities. Data on the psychiatric assessment revealed that seven of the 12 subjects that completed the assessment received an anxiety diagnosis. Also, 75% of patients that had more than 50% hair loss received anxiety and depressive diagnoses, and only one of the 12 participants had a current depressive disorder. Another finding was that parents tend to project their own anxiety when responding to questions that their children would deny.

A study by Chu et al. (2011) examined the relationship between AA and various psychiatric disorders. The disorders included: (a) anxiety, (b) phobias, (c) obsessive-compulsive, (d) personality, (e) manic, (f) major depressive, (g) bipolar, (h) schizophrenia, and (i) attention deficit. They found that patients younger than 20 years old had a higher risk of major depressive disorder. No relationship was found between any other disorders. Ghanizadeh (2008) also conducted a study on psychiatric disorders in children and adolescents with AA. They also found that the most common disorder was major depressive disorder.

Bilgic et al. (2013) conducted a study to determine the psychiatric state and health-related quality of 74 children and adolescents ages 8-18 with AA. Questionnaires were used to examine their psychiatric state and health-related quality of life. A control group contained children of similar age, gender, and education of parents. Two age groups were created, children 8–12 years and adolescents 13-18 years. The results found that levels of anxiety were higher in the child group as well as evidence of depressive mood. They also found that AA had an impact in the daily life of children and

adolescents. In addition, the patient age at onset and severity of AA did not link with anxiety and depression scores in either age group.

Colon et al., (1991) conducted psychiatric interviews using the Diagnostic Interview Schedule (DIS) with 31 participants over a 30 month interval. The age range of the participants ranged from 17 to 59 years. Twenty-two were female and nine were male. Twelve of the participants reported that they had received previous psychiatric treatment for anxiety and depression. They found a significant relationship between a psychiatric diagnosis of anxiety and AA, but not with depression. They also noted that three-quarters of their participants had no difficulty coping with AA and that wigs were viewed as a viable option.

Potential Types of Coping Strategies

People cope with AA differently as the course and severity of the condition varies widely. Individuals with AA have found that communicating with others with AA can help them better manage their condition. These individuals realize that they are not alone and can gather information from others as to (a) doctor references, (b) treatments, (c) coping strategies, and (d) support groups (Kalabokes, 2011).

Medicinal treatments. The research findings indicate that there is not one specific medicinal treatment that works in every case of AA. The treatment for AA usually coincides with the motivation of the patient involved. Topical steroids and injections of steroids are commonly used as are topical corticosteroid creams and can achieve good results, but not in all cases (MacLean & Tidman, 2013). Individuals also need to be monitored for side effects.

Kose, Sayar, and Ebrinc (2000) completed a study comparing before and after psychological effects of treatments on individuals with AA. The participants were 18 males in their twenties. The treatment selected was injections of intralesional triamcinolone acetanide, a corticosteroid, every three weeks. Depression, anxiety, and hopelessness scales were used and found that hair growth was not associated with psychological well-being. They suggested that the limitation of their study was that the length was too short to assess the psychological well-being of their participants and that future research should include a placebo controlled design. Gilhar, Etzioni, and Paus (2012) concur that intradermal injections can stimulate regrowth.

Various treatments are presented in a study by Mounsey and Reed (2009), with the most common being corticosteroids or minoxidil (Rogaine). Treatment can stimulate hair to grow, but growth stops when treatment is withdrawn. Individuals diagnosed with AT or AU are given a poorer diagnosis of recovery than someone experiencing AP. Hunt and McHale (2005b), in their article on the psychological impact of AA, state that people with AT and AU are less likely to respond to treatment, and it is estimated that approximately 7% to 30% of all alopecia cases are in these two forms. Minoxidil is commonly used, particularly with patchy AA, but is not effective on patients with AT or AU (McDonald Hull et al., 2003). For 20 years it has been used to stimulate hair growth, but its action is not totally understood (Alkhalifah, 2013). This over-the-counter treatment is readily available, but individuals need to be cautious and aware of the risks and side effects of treatment before they begin. Georgala, Befon, Maniatopoulou, and Georgala (2007) also note that minoxidil can affect heart function and cause a very rapid

heart rate and dizziness. This drug was also found to cause low blood pressure and abnormal pulse rates. They suggest future studies to safeguard vulnerable populations.

Treatments used for children are discussed in an article by Mukherjee, Burkhart, and Morrell (2009). They note that AA is common in children, but can be psychologically difficult to handle. The most common treatments for children include: corticosteroids, minoxidil, topical immune suppressants, and immune sensitizers. Although a common treatment, the effectiveness of corticosteroids is in question. An unpleasant side effect of minoxidil is that it causes unwanted hairiness on women especially in places where excessive hair is unusual, like the face. Intralesional triamcinolone acetonide injections, which are FDA approved, are also used for this group of individuals. Again, the efficacy of this treatment is uncertain. They comment that these treatments are a watch and wait process as some treatments are not tolerated well, or are ineffective. Hairpieces can be helpful while waiting for a positive outcome of a particular treatment. They conclude by indicating that this disease can be psychologically distressing and that future research is needed for new treatments to be discovered.

Nield et al. (2006) also explains that when AA persists, treatment then needs to begin and topical corticosteroids are usually the drug of choice. Intralesional triamcinalone injections, as mentioned previously, have had positive success rates, but can be painful. Topical sensitizers are used that produce an allergic reaction, such as, diphenylcyclopropanone, which causes itchiness and inflammation (Mukherjee et al., 2009). Another topical sensitizer, anthralin has been found to stimulate hair growth as

well as dinitrochlorobenzene (DNCB) which is no longer used because of concerns of carcinogenicity (Alkhalifah, 2011; Papadopoulos, Schwartz, & Janniger, 2000). Harrison and Sinclair (2003) agree that anthralin can be effective and is used when topical corticosteroids are ineffective. However, they address undesirable reactions such as (a) itching, (b) scaling, and (c) redness or inflammation at the site.

MacDonald Hull, Wood, Hutchinson, Sladden, and Messenger (2003) found similar treatments and outcomes. Topical corticosteroids are widely used as treatment and they add that a common side effect is inflammation, which causes a rash or itching. Corticosteroid injections can also stimulate hair re-growth. However, these treatments have not been promising or long lasting. Many have to be reapplied regularly to maintain results. Also, many are not recommended for long term use due to possible short and long term risks, such as the breakdown of tissues.

Alternative treatments. Treatment can be challenging in that there is not a universal remedy. Many participants in the Hunt and McHale (2005a) study were stressed to find out there is no cure. Some try alternative therapies, because typical steroid therapies have side effects. However, these can be expensive, and the user ends up feeling discouraged. A participant in their study was discouraged by steroid treatments and tried an herbal remedy using, “a mixture of coconut oil with rosemary oil; aloe vera and rosemary extracts; magnesium tablets” (p. 45). The efficacy of this treatment was not confirmed and the authors indicate that individuals will try alternatives when one treatment fails to work successfully.

Ultraviolet light therapy (PUVA) has been successful, although, it has been linked to skin cancer (Papadopoulos, Schwartz, & Janniger, 2000). Harrison and Sinclair (2003) also commented that PUVA is not recommended for children because of the possibility of developing melanoma. Again, these therapies need to be continued on a regular basis in order to maintain desired results. Risks and side effects should be addressed prior to experimenting with alternative treatments.

Shenefelt (2003) used hypnotherapy as an alternative treatment for several dermatologic conditions. He comments that, hypnosis can regulate the blood flow through the body and this can in turn cause relaxation, which leads to lower stress levels. He concludes that hypnosis could be an additional support to the primary treatment of choice. Willemsen and Vanderlinden (2008) conducted a study of 21 patients with AA in which the patients were treated with hypnosis. The patients were encouraged to imagine hair growth and body healing. Although some hair growth did occur, it was difficult to determine if hypnosis alone was solely responsible for the growth as other treatments were also in place during their intervention. The hypnotherapy, however, did result in decreased anxiety and depression, which improved the well-being of their patients. In a similar study, Willemsen, Vanderlinden, Deconinck, and Roseeuw (2006) hypnosis was used on patients with AP, AT, and AU. They found significant hair growth in 12 of their patients. However, alternative treatments were also being used concurrently. They did comment that the well-being of their patients improved including lower levels of scores on anxiety and depression scales.

An article by Tosti and Gray (2007) examined the impact that hair disorders have on individuals. They discuss treatments that can improve the look of an individual's hair including shampoos and conditioners. This type of holistic treatment can improve the ease in which the hair is styled and can add bulk to the hair to the remaining hair. Although these products can enhance the way hair looks and feels, they are sometimes used incorrectly and could result in changes or damage to the hair. Participants in a study by Welsh and Guy (2009) commented that medical practitioners often recommended shampoos and creams as treatments to restore hair.

Massage and relaxation therapy was used in a study by Putt, Weinstein, and Dzindolet (1994). This case study centered on a 16-year-old male with a five-year history of AA. They used hair massage, relaxation tapes with visual imagery, and a monetary reward. They found that hair loss not only decreased, but the patient had a full head of hair within 14 months. However, the researchers could not verify that their interventions were the sole reason for hair growth.

Welsh and Guy (2009) conducted a study on four men and seven women analyzing their coping and adjustment skills in managing their AA. They used treatments such as shampoos, creams, and liquids, and when these proved ineffective, they tried the steroid creams and injections. When all else failed, some tried heat treatments, herbal remedies, and acupuncture.

Cash (2009) completed a study of men with male pattern baldness and their choice of treatments to reverse their hair loss. Many participants tried alternative treatments like shampoos, vitamins, and laser combs prior to consulting with a physician.

When these treatments proved ineffective, a consultation with a physician was imminent to discuss treatments involving medication or a hair restoration procedure.

Cosmetic cover-up. Young people with AA may have difficulty maintaining intimate relations, coping in school, handling reactions from peers, and teasing. These complications lead to longer absences from school (Hunt & McHale, 2005a). In their study on the psychological issues of AA, Hunt and McHale (2005a) found that most of the fear associated with this condition was linked to the individual's altered appearance. The participants in their study used words like, *dread*, *ashamed*, *hideous*, and *lonely* when describing how they felt. Coping was also difficult as hairpieces caused concern on windy days or active life styles.

The most common cosmetic cover-ups are hairpieces (Draelos, 2011) and various types are available depending on the circumstance. Many individuals become distressed when wearing wigs in hot weather, windy weather, and during sport activities (Hunt & McHale, 2005a). Although, one woman commented positively that she no longer had to visit her hairdresser and a mother with a young daughter commented that having a bald child was a convenient way to discourage solicitors. Coping by way of cosmetic cover-up takes on many forms: (a) hats, (b) scarves, (c) hairpieces, (d) hair systems (extensions), and (e) permanent make-up because it can affect a person's personal life, social life, and work life (McKillop, 2010). The loss of hair in women was considered a social and cosmetic liability (Gallagher, 1997) and many wore a wig as a prop. Others found wigs uncomfortable and strange (Vandegrift, 1994). These individuals just did not want to attract unwanted attention (Welsh & Guy, 2009).

Choosing to wear a hair piece could prove overwhelming due to the variety of options and expense (Messenger et al., 2012). Dinh and Sinclair (2007) explored female pattern hair loss and found that hair reveals femininity and identity. Coping is difficult and psychological distress is noted in feelings of guilt, insomnia, low self-esteem, and limited social interactions. Hair styling products vary according to the skin conditions of the scalp. These authors also mention other options to those with hair loss. Camouflage products like powders are used on oily skin, whereas, creams are used on dryer scalps. They also note that some products build hair fibers to create a thicker look. Hair extensions can also create a fuller look and hair pieces are used for extensive hair loss. Surgical treatments are available, but complications can occur and the results may not be what the patient expected.

In the Hunt and McHale (2005a) study, one participant remarked that their negative appearance equated to being pig-like because of their lack of lashes and eyebrows. Eye lashes and eyebrows help define a person's face. Sometimes people make assumptions that individuals with AA have cancer and are undergoing chemotherapy (McKillop, 2010). Permanent make-up is a technique that uses tattoos to enhance and give definition to the face. It can add definition and color to a person's face, lips, eyelids, and eyebrows. The function of eyebrows and eyelashes to protect the eyes from foreign particles is now gone and applying fake eyelashes and brows that look natural can be tricky (Messenger et al., 2012). They also note that the quality of these fake products have improved to last multiple days.

Locks of Love, is a not-for-profit organization that collects hair for the purpose of constructing hairpieces for children with long-term hair loss. Silverberg (2006) found that the Locks of Love organization has given children their lives and confidence back by providing them with a coping tool, namely hair. They state that self-esteem and socialization is vital to a child's well-being and that girls face more challenges when coping with hair loss.

Community and outside support. Support groups bring comfort and a sense of belonging to many people who think they are alone with a disease. However, sometimes support groups are not well advertised and are then overlooked by individuals needing support. When social supports are not available, the ability to cope subsides (Hunt & McHale, 2005b). Harrison and Sinclair (2003) indicate the importance of support groups for parents and then later for children when they become more aware of their AA. Patient support groups can assist children and adolescents in dealing with their altered appearance (MacLean & Tidman, 2013). Adolescents reported that when they were experiencing low levels of depression they would consult their friends and family (Sawyer et al., 2012). However, adolescents experiencing higher levels of depression tended to keep to themselves, which could lead to suicidal ideation. Sawyer et al. also noted that females would seek help more frequently from friends, school counselors, and telephone help lines, whereas, males would consult with medical practitioners and the internet. Comments from participants in a study by Welsh and Guy (2009) revealed both negative and positive support group experiences. One participant noted their support group experience as being depressing and negative. Another stated that the support group

was better therapy than any treatment received. This could have something to do with the expectations one has prior to attending a support group meeting. Parents who attend the National Alopecia Areata Foundation (NAAF) conferences with their children may feel less isolated and alone due to support. They feel normal among others who look like them (Prickitt et al., 2004). The NAAF has support groups in 41 states and eight countries worldwide. These groups promote healing support for individuals affected by AA. People who are experiencing the same issues are often the best support and resources for those newly diagnosed (NAAF, 2011c). NAAF also suggests that if an individual is overwhelmed, a mental health professional may be helpful to sort out anxieties and learn coping skills.

A participant in a study by Welsh and Guy (2009) commented that, “Yes, I do have my moments and do have times where I think it’s unfair and have a sad day but I generally try to give myself a kick up the backside as there are many worse things that you can get” (p. 198). Hunt and McHale (2005a) remarked that several of their participants just shaved their heads to finalize the loss of hair. Other participants suggested that more should be done for help and support. The physicians treating individuals for AA perceive the condition as an insignificant dermatological problem. However, it is more than skin deep.

Communication/technology. The NAAF has numerous resources for individuals to connect with others from pen pal programs, resources on hairpieces and counseling to a Facebook fan page and a Twitter page (National Alopecia Areata Foundation, 2011c). Maintaining friendships is important for children and adolescents and the internet has

numerous sites to stay in touch like Facebook, Twitter, Instagram, and Myspace. Young people use these sites to interact and relate to peers online (Subrahmanyam, Reich, Waechter, & Espinoza, 2008). They also use sites to connect with relatives and family members. Subrahmanyam et al. (2008) reported that 63% of their study participants spent time on social network sites on the day they completed the survey. A study by Valkenburg and Peter (2007) found that communicating with friends online established a closer relationship with friends. In addition, they did not find a difference between genders or ages. Parents are often concerned about giving unlimited freedom to their young children. Children were surveyed through NAAF and some of their suggestions and comments were to tell classmates about AA so that they have an understanding. Also, attending conferences, support group meetings, ball games and fundraisers have raised awareness and new relationships have formed (NAAF, 2011b).

The NAAF created a school packet titled, *“Education on the Move”: A Project Promoting Alopecia Areata in the Elementary School Classroom* (n. d.). This handbook promotes awareness and shares information on dealing with alopecia areata in the classroom. It addresses potential self-esteem issues, ideas from parents, projects and fundraisers, recommended readings, as well as the construction of a 504 plan.

Family support. Hunt and McHale (2005a) discovered that family support was not always available. Family members had difficulty comprehending the impact of the loss and found adapting to a member with AA difficult because of the changing identity. Parents are encouraged to learn all they can about AA and be honest with their children (NAAF, 2011a). Hunt and McHale (2005a) suggest that those who did not have support

from family and friends contact local support services. The younger people in their study found challenges in maintaining intimate relationships, coping in school, managing reactions from peers, and teasing. This often led to longer absences from school. They also found that extreme situations existed where individuals could no longer cope and had considered suicide as an option. Parents need to identify changes in the needs of their children and adolescents with AA, and if needed, refer to a licensed professional (Messenger, 2012).

Individuals in a study by Welsh and Guy (2009) commented that support from family and friends gave them feelings of acceptance. Although others felt like a pariah in their own home, had very little support, and were left on their own to cope with their condition. NAAF (2011a) states that parents should let their child know they are special and love them unconditionally with or without hair. Support networks of family and friends can improve an individual's self-esteem and encourage positive social interactions (Rumsey & Harcourt, 2004). Additionally, family support in times of personal difficulty can alleviate fears and reduce stress.

Elkin, Hilker, and Drabman (2006) completed a case study of a 13-year-old white female and reported that parents presented with more anxiety than the child with AA. The parent's concern could possibly be the unwanted attention or harassment their child may face. The authors observed that cosmetic changes in a family member can effect and increase levels of distress in a family. These findings were based on the Children's Depression Inventory (CDI), and a Revised Childhood Anxiety and Depression Scale (RCADS). An intervention of behavioral and cognitive-behavioral strategies was also

used. The psychologist hoped to introduce coping strategies and problem solving. There was some initial anxiety on the part of the child as to the change in appearance. While the child was functioning well after treatment, she still expressed concern about her new identity. The researchers also stressed that interventions need to include all family members in order to reduce family distress. Heaven and Ciarrochi (2008) found a link between a child's self-esteem and type of parenting method. They found that a parenting style that included placing limits on children, being responsive to their demands, encouraging them, and a willingness to negotiate in a loving environment produced children with higher levels of self-esteem. Parenting styles that included some form of punishment led to the opposite results.

NAAF, in their Parent's Guide brochure (NAAF, 2011a) provides parents with valuable advice when trying to make sense their children's AA. They suggest that parents educate themselves about this condition, answer questions honestly, not let AA define who their child is, and to be sensitive and listen to their child.

Table 1 presents a summary of the potential impact factors based on the literature review. Table 2 presents the types of coping strategies based on the literature review.

Table 1

Literature Review-Based Impact Factors

Category	Impact Factors
Psychological Effects	<ul style="list-style-type: none"> • Stress • Depression/sadness • Anxiety • School Issues • Insecurities/inadequacies • Withdrawal • Embarrassment • Discouragement • Guilt
Advocacy/Acceptance	<ul style="list-style-type: none"> • Self-image (negative vs. positive) • Confidence • Independence • Self-worth • Vulnerability • Ability to cope • Use of humor
Personal Appearance	<ul style="list-style-type: none"> • Distress/concern • Self-image (negative vs. positive) • Discrimination • Peer abuse/bullying • Behavior problems/aggression • Socialization • Isolationist
Support	<ul style="list-style-type: none"> • Family • Friends • Groups

Table 2

Literature Review-Based Coping Strategies

Category	Coping Strategy
Medicinal Treatments	<ul style="list-style-type: none"> • Consultation with various doctors • Over-the-counter (Minoxidil) • Prescriptions (anti-depressants, anti-anxiety) • Injections • Prescriptions (creams, lotions, solutions)
Alternative Treatments	<ul style="list-style-type: none"> • Massage • PUVA (light treatment) • Hypnosis • Relaxation training • Shampoos/conditioners (volume enhancing products) • Diets/vitamins • Acupuncture • Surgery (hair plugs)
Cosmetic Cover-up	<ul style="list-style-type: none"> • Hats/scarves • Hairpieces • Make-up • Permanent make-up
Community/Outside Support	<ul style="list-style-type: none"> • Support groups • School support/acceptance • Individual counseling • Professional organizations • Research participants • Medical experts
Communication/Technology	<ul style="list-style-type: none"> • Online support from friends • Educating and telling others online • Personal written accounts • Use of social network sites (Facebook, Twitter) • Research online information • Chat rooms
Family Support	<ul style="list-style-type: none"> • Educating others/awareness • Encouragement • Protection • Connecting with other families with AA

Summary

Alopecia areata can be a difficult condition to manage daily. It presents in many forms like AA, AT, and AU and runs an unpredictable course with remissions and relapses. The ability to perceive oneself positively with an obviously altered appearance is difficult and the self-esteem in individuals with AA can be fragile. There is no cure and most treatments are ineffective, uncomfortable, or risky. The use of coping strategies is a practical choice with hairpieces being the most commonly used. Acceptance at home, with friends, at school, and in the workplace would be ideal, but some individuals are not as fortunate as others. Community supports are available but pushing aside societal norms is complicated. Education and awareness are important when developing a constructive plan of support. Although many coping strategies are used by individuals with AA, research does not definitively state why these strategies are chosen, except for the fact that these are the only viable options available at present.

Limited studies exist addressing the emotional support and coping strategies needed by children and adolescents with AA. The articles that are solely children and adolescent based focusing on: (a) depression, (b) stress, (c) autoimmunity, (d) life events, and (e) treatments. Identity issues could be troublesome for this group of individuals. Therefore, this study hopes to discover the impact factors most frequently used by children and adolescents in order to manage their AA and minimize negative self-perception issues.

3. METHODS

This study investigated emerging impact factors experienced by children and adolescents with alopecia areata (AA) as well as the coping strategies they use. As previously stated AA is an autoimmune disease that results in the loss of hair on the scalp and elsewhere on the body and does not discriminate between genders, age, or race (Papadopoulos et al., 2000). A mixed methods design was used to conduct this study. A survey was developed, validated, and piloted to test the procedures and survey instrument. The national study was then initiated, the survey was sent to members of NAAF and participants were recruited for follow-up interviews. The data were then analyzed using a factor analysis, t-tests, ANOVAs, and grounded theory comparison.

Research Design

In an attempt to adequately understand the factors that impact children and adolescents with AA and the strategies they use to manage this condition, seven research questions were addressed using a mixed method approach. To reiterate, the seven questions included:

1. What are the factors that impact children and adolescents with AA?
2. What types of coping strategies are used by children and adolescents with AA?

3. How do the impact factors differ by group (e.g., age, gender, onset, and duration)?
4. How do the types of coping strategies used differ by group (e.g., age, gender, onset, and duration)?
5. Which individual impact items have the greatest and least influence on children and adolescents with AA?
6. Which types of coping strategies are used most and least frequently by children and adolescents with AA?
7. How do children and adolescents describe the experience of having AA over time?

A mixed method explanatory research design was used to gather data because collecting data in a two-phase method would enhance the final results (Creswell, 2008). Collecting the quantitative data first could give a generalized idea of the research problem. The second phase of gathering qualitative data would explore and refine in more detail the results collected from the quantitative phase (Creswell, 2008).

According to Driscoll, Appiah-Yeboah, Salib, and Rupert (2007), using more than one research method would increase the strength of the final results. This would be accomplished by conducting an electronic survey then posing interview questions that would explore survey responses in more detail. Driscoll et al. (2007) explained the importance of collecting data sequentially in phases, in order to use the qualitative follow-up to delve more deeply into the quantitative responses by exploring any weaknesses or insufficient results gathered in the initial quantitative phase. The process

would involve collecting qualitative data that would contribute ideas or insight gathered from the quantitative first phase. Creswell (2008) explained that when using an explanatory design, the quantitative data is introduced first as it represents the majority of the data while the qualitative data is used to refine the quantitative results.

Four independent variables (IV) were identified for analysis: (a) age, (b) gender, (c) onset, and (d) duration of AA. The two dependent variables (DV) include the impact factors and coping strategies. These will be discussed further.

Sampling

Purposeful homogeneous sampling was chosen for this study as the focus is on a specific group of individuals who have similar traits and characteristics (Creswell, 2008). The children and adolescents recruited for this study were living with AA, would most likely understand the questions associated with this disorder, and would be able to provide authentic responses. These participants were limited to children and adolescents ages 10 through 19 years of age. This group encompasses individuals from later elementary school through high school (American Psychological Association, 2002). Specifics regarding participants for the pilot and national phases of the study are provided in those sections.

Ethical Considerations

An Institutional Review Board (IRB) application was completed for the study and submitted through the researcher's university. The foreseeable risks or discomforts included the need to ask some personal questions about family history and possible

psychological effects of this medical condition in order to get a better picture as to how this condition had affected the participant. Extremely negative options were excluded (e.g., suicidal thoughts, drugs). Otherwise, there were no potential physical, social, or legal risks to the participants of this study. NAAF was consulted for their collaboration with this research and approval was granted (see Appendix A). A cover letter introduced the survey and explained the purpose of the study, how the data would be used, and the confidentiality of the study (see Appendix B).

Consent and assent documents were created according to the IRB. Three separate documents were created in order to include all participants. They included: (a) an informed consent for the parent of children and adolescents under 18 years of age, (b) an informed assent for the child or adolescent under 18 years of age, and (c) an informed consent for the 18 and 19 year old participants. Three sets of these documents were created. The first set of documents included a signature line for the participants to sign prior to a follow-up interview or focus group (see Appendix C). A second set of documents was added prior to the initiation of the pilot survey (see Appendix D) and solicits volunteers for a focus group. The third set of documents was added prior to the initiation of the national survey (see Appendix E) and solicits volunteers for a follow-up interview. Only participants who chose to accept the consent/assent were given access to the survey. The parents, children and adolescents under 18, and the 18-19 year olds were required to click on a box that stated that they agreed with the consent/assent in order to gain access to the survey. The assent form for children and adolescents ages 10-17 did not appear until the parent or guardian of these individuals had clicked on their approval

of the consent. Once the consent/assent form(s) were accepted, the participants were given immediate access to the survey. The cover letter and assent form were written at a seventh grade reading level, as indicated by the Readability Statistics program in Microsoft Word.

Prior to the follow-up interview, paper copies or electronic copies of the consent/assent forms were provided to the participants and a family member for their signatures. Extra copies were also available for the participants to keep for their records. In addition, the forms were also scanned and saved as a word document as several Skype participants requested their copy electronically. Some consent/assent forms had to be mailed to the interviewees of a Skype interview as they had difficulty opening the word document that contained the forms or were unable to print a copy of the document to sign and then scan back to the researcher.

Survey Development

The original survey questionnaire was generated by the researcher based upon the literature review. It was designed to ask probing questions to identify factors that impact children and adolescents with AA and strategies they use to cope. While creating the instrument, the researcher reviewed several inventories used in previous studies to help develop questions. One instrument that was examined was the Appraisal Dimension Scale used by Kyser (1993). This instrument was used to measure attitudes individuals had toward their AA. Other instruments examined were the Social Activity Questionnaire and an Alopecia Group Demographic and Descriptive Questions survey used by Raquepaw (1990) in her dissertation on the psychological effects of alopecia.

The original draft of the survey included 68 questions (see Appendix F). The questions were written at a seventh grade level as indicated by the Readability Statistics program in Microsoft Word. A four-point Likert-type scale was used with no neutral option. Borgers, Hox, and Sikkel (2004) conducted a study on the effects of surveys on children and suggested that limiting the survey to a four-response scale would be the most favorable option for children. They also noted that given the cognitive development of children, a neutral midpoint may be a tempting option rather than thinking through an answer choice. Patten (2011) concurs that a neutral response may compel an individual to take the lazy way out rather than consider his/her actual feelings. All participants in this study were currently living with or have lived with the medical condition of AA and have an adequate knowledge base. Therefore, they could easily be nudged into answering in one of the two directions of agree or disagree (Fowler, 2009). Closed-ended questions were also used as they limited the respondents answer choices. Fowler (2009) suggested that closed questions were easier to collect and interpret. He also commented that respondents may interpret response choices differently. In addition to prevent a non-response to a particular question, the survey was set up to require a response in order to move on to the next question (Dillman et al., 2009).

The survey directions and questions were short and concise so that the participants would stay engaged and read the entire statement (Dillman et al., 2009). Fowler (2009) explained the importance of a self-administered survey: (a) it should be self-explanatory, (b) should only include closed answers, (c) questions should be limited, and (d) questionnaire should be simple and clear. He maintained that the respondent

should be given tasks to complete in a layout that is clear and orderly. He also stated that the tool itself should be self-explanatory, and that directions should not be a necessary component. However, short directions were included in the survey. Fowler (2009) adds that self-administered online surveys are also cost effective, lead to a rapid response time, and could be taken at a time convenient to the participant.

Survey Validation

Prior to initiating the pilot study, a validation survey (see Appendix G) was sent to the 12 NAAF Board of Directors for their expert review as well as a small panel of four children and adolescents to assess the content validity of the instrument. This is an important step as it confirms the content area, level of difficulty of the questions, and whether the questions are valid (Creswell, 2008). Lawshe (1975) also mentions the importance of the experts when determining the validity of a test.

The Board member experts, far from being homogenous, introduced different perspectives. The Board members were from diverse backgrounds such as: (a) business owners, (b) account executives, (c) business managers, (d) artists, (e) researchers, (f) homemakers, (g) dentist, (h) doctors, and (i) TV hosts. These experts in the field had an interest in the foundation because they have either acquired AA, a friend or family member has the condition, or because AA is a medical enigma to those in the field. They all support research in order to find a cure or treatment for AA. The validation survey was sent to the Board members via e-mail as members were located all over the country. They were given information as to the purpose of the study, the research questions, and

how the data would be analyzed and used and were encouraged to review the survey and modify it to their discretion. Five NAAF Board members responded.

At the same time, a child and adolescent panel was also secured through the local support group to examine the importance and relevance of each question on the survey. The purpose of the study was explained to this group as well as the value of their input. This group of four children and adolescents with AA between the ages of 10 and 19 were asked, (a) how they would answer each question, (b) if the questions were clear and simply stated, (c) what they were thinking when answering the question, (d) their interpretation of what the question was asking, and (e) if any relevant questions were missed. The child and adolescent panel was held at the home of a young girl with AA. Three children and adolescents ages 12, 17, and 19 attended this meeting to rate the questions. Another young girl, age 14 also wanted to participate, but did not want others to know that she had AA. The validation survey was sent to her via e-mail and her responses were added to the results. After arriving at the home where the meeting was to take place, the participants were introduced to one another. The researcher placed 10 different colored pens on the meeting table and the participants were instructed to choose their favorite color for recording their responses on the paper copies of the validation survey rather than their name to maintain confidentiality. Each question and answer choices were read aloud and the participants were asked if they understood the question and if they had concerns or suggestions relating to the question. They were encouraged to discuss questions with each other, yet the age differences and unfamiliarity with one another prevented a rich discussion.

The survey items were measured using an adaptation of the approach developed by Lawshe (1975). Content validity, examines the extent to which the test items are representative of all possible questions (Creswell, 2008) and was measured using the statement of “essential statement to include,” “useful statement, but not essential to include,” and “statement is not important to include.” Values of a 1, 2, or 3 were computed for each question. A “3” indicated that the statement is essential to the study. A “2” implied that the statement is useful, but not essential, and a “1” suggested that the statement is not important to the purpose of the study. The intent was to adhere to the following plan: (a) If more than half of the respondents responded to a question with a 3, then that particular question or statement was kept in the survey as it showed that there was some level of content validity; (b) If the check marks were spread more evenly over 3s and 2s, the dissertation director and researcher made a decision to keep or discard the question; (c) If checks in 1 were overwhelming, the question was discarded. This approach, however, was modified as one board member mistakenly answered the demographic questions rather than rating them. Therefore, it was decided that using a percentage was a more useful and accurate way to rate the responses, so the responses from the board were calculated as percentages in all three scales along with the responses from the children and adolescents (N=9). Any response below 20% was thrown out and responses over 50% were accepted. Any responses between 30% and 40% were discussed (see Appendix H).

The survey was validated by five members of NAAF’s Board of Directors and four children and adolescents with AA. The results reflected some unclear or incomplete

questions, which were revised for clarity. For example, suggested words were added e.g., “to disguise my hair loss,” “for my hair loss” to make a few questions more specific. In order to maintain consistency, the acronym “AA” was changed to alopecia areata. Two questions that appeared redundant were combined with another to create one straightforward question. Terminology or specific treatments that were unclear to the children or adolescents were either revised or the entire question was eliminated. For example, the word “peers” was changed to “classmates” and “PUVA treatments” were eliminated. No major modifications were made. IRB was notified as to these changes and approval was given to use the shorter survey.

Based on the Board members and the children and adolescent feedback, all statements were clarified. The initial survey consisted of 68 questions. After review and modifications, the validated survey was reduced to 56 questions (see Appendix I).

Revised Survey

The first 43 questions addressed the dependent variables of potential impact factors of AA and coping strategies used based on a four-point Likert-type scale with no neutral option. The last 13 prompts were to obtain independent variables and other demographic information (see Appendix I).

A four-point response scale was used in answering the 43 impact factor and coping strategy questions. There were 28 impact factor questions and 15 coping strategy questions. The researcher was able to place one coping strategy question between every two impact factor questions beginning with question one. Therefore, questions 1, 4, 7,

10, 13, 16, 19, 22, 25, 28, 31, 34, 37, 40, 43 asked about coping strategies used in managing AA.

The response scale included the following options with corresponding point values: Strongly Agree (4), Agree (3), Disagree (2), and Strongly Disagree (1). Eight questions (12, 15, 17, 21, 26, 29, 33, and 36) offered a reverse response option to control for response set. This means that the eight items would be scored in the opposite direction of the response scale (Green & Salkind, 2011). This was accomplished by recoding the eight questions in SPSS as follows: Strongly Agree (1), Agree (2), Disagree (3), and Strongly Disagree (4). Demographic information response choices varied.

Independent Variables

The following independent variables (IV) were analyzed in this study: (a) age, (b) gender, (c) duration of diagnosis, and (e) age when diagnosed. Age categories were determined based on the stages of adolescent development reported by Spano (2004). Ages were divided into early adolescence 10-13, mid adolescence 14-16, and older adolescence 17-19. Duration categories were based upon a midpoint split by taking the number of participants (237) and dividing by two to get 118.5. The frequency totals for each of the number of years having AA were added until the total was equal to or just short of the 118.5. The frequency for the first six years added to 116. This was the cut off between short and long duration. Onset of AA was also determined by inspecting the frequency distributions. In this instance the number of participants (237) was divided by three (79) in order to secure a young, mid, and older onset of AA. The frequency totals for each number of years were added to secure a total of approximately 79. The

groupings that emerged were a young diagnosis of 1-5 years, mid-range diagnosis of 6-10 years, and an older diagnosis of 11-19 years. Additional demographic information was also collected and assessed in order to gain a better understanding of the participants' background. They include: (a) ethnic background, (b) student status, (c) change of schools, (d) special education classes, (e) bullied, (f) region of residence, (g) location within the region, (h) current AA status, and (i) AA family history (see Table 3).

Dependent Variables

The dependent variables (DV) in this study are the factors that impact children and adolescents with AA and the strategies they use to cope. The DVs assess the social, psychological, and emotional responses of children and adolescents dealing with this condition. The impact factors accounted for 27 items and the coping strategies accounted for 15 of the items. As a final measure, interviews were conducted to determine the effect these impact factors and types of coping strategies have had on the lives of children and adolescents with AA.

Table 3

Summary of Independent and Dependent Variables with Corresponding Survey Questions

Independent Variables	Location
Age	Question 44
Gender	Question 45
Age of onset	Question 53
Duration of diagnosis	Question 56
Dependent Variables - Impact Factors	Location
I enjoy going out with my friends	Question 2
I can make friends easily	Question 3
I usually go bald during most of the day	Question 5
I think about my positive qualities once a day	Question 6
Having AA does not bother me	Question 8
I would like to have a full head of hair	Question 9
My teachers accept me for who I am	Question 11
I avoid being around people	Question 12
I get along well with my family	Question 14
I often fear being rejected by others	Question 15
I prefer to do things by myself	Question 17
I have told my friends about my AA	Question 18
I feel that I am a special person	Question 20
I have a hard time making friends	Question 21
I am okay with the way I look	Question 23
I enjoy hanging out at the mall with my friends	Question 24
I am afraid to tell my friends	Question 26
People have made fun of me	Question 27
Having AA makes me angry with myself	Question 29
I participate in sports with my friends	Question 30
I can do things as well as my classmates	Question 32
I think about my hair loss daily	Question 33
I feel that I have the same opportunities as others	Question 35
I often cry about my hair loss	Question 36
I have accepted my hair loss	Question 38
I have many good qualities	Question 39
I have continued to live my life as it was before	Question 41
I would never change the way I look	Question 42

Dependent Variables - Coping Strategies	Location
My family helps support me	Question 1
I wear hats/scarves/do-rags/skull caps	Question 4
I use prescriptions from the doctor to feel better	Question 7
I have had individual counseling	Question 10
I use make-up (eyeliner, eyebrow pencil, etc.)	Question 13
I have attended support group meetings	Question 16
I have gotten scalp injections	Question 19
My family and I have attended professional conferences	Question 22
I have used prescription creams	Question 25
I wear hairpieces all the time	Question 28
I tell people about my AA	Question 31
I have tried different diets (dairy, protein, etc.)	Question 34
I have tried different types of shampoos and conditioners	Question 37
I have looked up information and resources online	Question 40
I use social network sites to talk to friends	Question 43
Other Demographics	Location
Ethnic background	Question 46
Student status	Question 47
Change of schools	Question 48
Special education classes	Question 49
Bullied	Question 50
Region of residence (e.g., NE, SE, Midwest)	Question 51
Location within region (urban, suburban, rural)	Question 52
Current AA status	Question 54
AA family history	Question 55

Piloting of Survey

The validated survey was initially tested using mock test responses. Response options of: Strongly Agree, Agree, Disagree, and Strongly Disagree should have reflected Strongly Agree with a value of 4, Agree with a value of 3, Disagree with a value of 2, and Strongly Disagree with a value of 1. However, when placed into SPSS, the first

option that appeared was automatically given the value of 1, the second 2, the third 3, and the fourth 4. Therefore, Strongly Agree was given the value of 1, Agree with a value of 2, Disagree with a value of 3, and Strongly Disagree with a value of 4, so the order in which the responses would appear in the survey were adjusted to gain the desired numerical sequence.

The pilot study was conducted to evaluate the instrument and determine if the responses could be successfully collected and analyzed (Dillman, Smyth, & Christian, 2009). Dillman et al. (2009) pointed out that pilots are essential when testing a new survey instrument and could identify nonresponse problems. Simon (2011) adds that pilots test the research protocols, instrument feasibility, and estimating outcomes.

Potential participants. Participants for the pilot phase of the study were recruited through the Virginia division of NAAF. The support group leader for this organization approved the process and provided contact information for 73 members, but was unable to identify how many of the 73 members had children or adolescents who met the criteria (e.g., ages 10-19 and AA diagnosis). The researcher provided additional Virginia contacts who had called NAAF but had not joined the foundation. These families became known to the researcher in her role as a telephone contact liaison for the foundation. In this role she fields inquiries from both members and non-members. During this process the researcher also was able to identify six families with children or adolescents meeting the criteria who were invited to participate.

The pilot study was limited to residents of Virginia to prevent overlapping respondents during the national survey. During the national phase of the study, potential

participants with Virginia zip codes were excluded. The opportunity for continued participation was offered to pilot participants via a question at the end of the survey soliciting volunteers for an interview of focus group experience.

Procedures. An e-mail invitation with a cover letter was sent to the 79 potential participants as blind copies, by concealing the name of the person being sent the e-mail from other recipients. This insures the privacy of all participants involved. The cover letter explained the purpose of the study, how the data would be used, as well as the confidentiality of the study. A link to the 56-question survey web site was attached to the cover letter. The researcher explained that the NAAF had given their support to conduct the study.

The survey was self-administered via e-mail. The cover letter contained a link for the participants to easily access the survey. This provided a quick and easy way to collect data (Creswell, 2008). A follow-up e-mail (see Appendix J) was sent to all participants one week after the initial survey as a reminder to complete the survey (Dillman et al., 2009) with a final reminder after two weeks (see Appendix K).

A Snap Survey was used to collect the quantitative data. The Snap Survey is a software program that can be used for questionnaires and data collection for online survey research (Snap Surveys, 2012). This type of survey was advantageous to the researcher in terms of expense, time, and data analysis. The data were then placed into a statistical program that separated out the data for specific analyses. Statistical Package for the Social Sciences (SPSS) was used for this process as data can be readily entered and variables were easily manipulated (Green & Salkind, 2011).

Outcomes. The pilot study generated 8 respondents out of 79 potential participants (10%). These 79 potential participants were not tracked as to how many opened or clicked at least one link in the e-mail message. There was also no way of knowing if the recipients had children or adolescents that fit the criteria of the study. While the numbers were small, Dillman et al. (2009) suggests that even a small pilot study is important in order to identify problems with the survey itself, as well as assessing the implementation procedures especially when executing a new survey. Studies have revealed benefits of conducting pilot studies no matter how small the outcome. Hertzog (2008) claimed that sample size of 10 or fewer could be sufficient in assessing the clarity and formatting of the instrument, but no reliability. Isaac and Michael (1982) also state the ease of working with smaller samples. Pilots test the research protocols, instrument feasibility, and estimating outcomes (Simon, 2011). The pilot tested the statistical program and determined the viability of the questionnaire for the larger national study (Dillman et al., 2009). As the pilot data were just used for testing the instrument and was not used in any analysis, it was decided that this data would be rolled over into the national study. Although it was not prudent to report Cronbach's Alpha with this small data set, a Cronbach's alpha was conducted on the national survey. The researcher was also able to secure one follow-up interview participant from the pilot.

National Distribution of Survey

Using the Krejcie and Morgan (1970) scale, it was determined that a representative sample size of 377 participants would be desirable to conduct this research. Dillman et al. (2009) concurred and added that a larger population sample

reduces sampling error and increased reliability. Specifically regarding factor analysis, Dimitrov (2012) suggested a minimum of 100-250. However, he also noted that a larger sample produces better factor solutions. Tinsley and Tinsley (1987) stand by the rule of 5-10 subjects per prompt. Taking this rule into account this study would then need approximately 280 to 560 subjects as the survey contains 56 questions. Furthermore, Comrey (1988) suggests that a sample size of 200 is adequate for 40 or fewer prompts. In addition, Comrey and Lee (1992) stated that 500 or more samples are preferable for most factor analyses. Given current response rate expectations for survey research and these established standards for effective analysis, oversampling to ensure a robust pool of actual respondents was suggested. Nulty (2008) formulated a guide for response rates vary and that measures can be taken to increase the results: (a) frequent reminders, (b) easy access by providing a survey URL, (c) rewards, (d) anonymity of responses, (e) limited questions, and (f) importance of responding.

Potential participants. The participants in this study included children and adolescents ages 10 through 19 whose parents or guardians are members of NAAF, and who volunteered to take the 15 minute online survey about impact factors and coping strategies used when dealing with their AA. These volunteer participants were recruited directly from the membership database at NAAF with the approval, assistance, and expertise of the NAAF staff. Any members with a Virginia zip code were excluded from the national study as several participated in the pilot study. The Foundation President and CEO, V. Kalabokes (personal communication, December 26, 2012) stated that their membership list was approximately 55,000. However, M. Cosgrove, NAAF's

Publication and Technology Director confirmed that they had approximately 16,000 viable e-mail recipients (personal communication, June 14, 2013). The survey was sent to this entire group of 16,000 as they could not isolate members with children or adolescents 10-19 years old with AA. M. Cosgrove stated that some of these members in their database may currently be older than the required criteria, while suggesting that members whose children were not currently in the age group of 10-19 could now potentially fit the criteria. In addition, G. Sherwood, NAAF's Director of Communications stated that NAAF currently had over 8,300 friends on Facebook as well as 1,450 followers on Twitter (personal communication, June 13, 2013). The survey was sent to these members as well. The survey was sent three times, over a three week period to 25,750 potential participants. Based upon demographics, all respondents who met the parameters of the study were included in the results.

Procedures. The national study was conducted in a similar fashion to the pilot except for the fact that the population consisted of all members of NAAF with the exclusion of Virginia. The survey was self-administered via e-mail and through social networks for the national study such as, e-mail, Twitter, or Facebook, so formatting was important. Twitter messages were limited to 140 characters (Hughes, Rowe, Batey, & Lee, 2012), so correspondence had to be set to that value (see Appendix L). The cover letter explained the purpose of the research and contained the embedded revised survey. The researcher coordinated through the Foundation to send the survey out to NAAF members. This final version of the survey was slightly modified at the end to include a response for a follow-up interview that could be completed via (a) telephone, (b) Skype,

or (c) in person. A reminder to complete the survey including the website was sent one and two weeks after the initiation of the survey, which, according to Dillman et al. (2009) could yield a higher response rate. The Snap Survey was used for data collection and SPSS was used for data analysis.

Outcomes. The national study, conducted over a three week period, generated 259 responses gathered from the NAAF membership e-mail, Twitter, and Facebook accounts. The data from the eight additional respondents from the pilot study increased the number of participants to 267. These data were visually inspected then cleaned. For instance, in accordance with study parameters, participants who indicated that their current age was less than 10 years old or over 19 years old were removed from the data set. There were 16 respondents who indicated that their age was less than 10 and 13 respondents who indicated that their age was over 19 for a total of 29 respondents who did not fit the study criteria. In addition, one respondent from the pilot indicated that his/her age was over 19. The dissertation chairman also visually inspected the data and monitored the cleaning process for possible errors (Basili, 2013). This reduced the total number of respondents to 237 participants. Details regarding participants can be found in the Results section.

An initial Cronbach's alpha was calculated at .525. Upon review of individual items, one was removed to increase the level to .551 ("I usually go bald during most of the day"). A Cronbach's alpha determines internal consistency and reliability (Cronbach & Shavelson, 2004). According to DeVellis (2012) a respectable score for a carefully constructed measurement instrument would be an alpha level above .80. Tavakol and

Dennick (2011) emphasize the importance of using Cronbach's alpha in establishing reliable test measures. They suggested that the test length be changed in response to attained values. The factor analysis also revealed that the same item did not cluster with any other items.

A Cronbach's alpha increases if the test items are correlated with each other (Tavakol & Dennick, 2011). The purpose of this study was to examine the impact factors and coping strategies of children and adolescents without measuring the same information. Fowler (2009) states the importance of creating surveys where the questions are limited, simple, and clear. Borgers, de Leeuw, and Hox (2000) add that children lack motivation and have difficulty concentrating with long questionnaires, which could result in poor data quality.

A mixed method design was used in this study so that the data from both methods would strengthen the results of the study. One method is not enough to address the research questions and obtain more information (Creswell, 2008). Therefore, the qualitative follow-up was initiated.

Qualitative Follow-up

The qualitative phase of this study was conducted to expand on the quantitative results and take into account the feelings and actions taken by children and adolescents with AA. The goal of the qualitative research was to enhance the quantitative findings by adding insight into the perceptions children and adolescents have toward their condition while justifying the need for additional research in this area (Maxwell, 2005).

Potential participants. Participants for qualitative follow-up interviews were purposefully selected from those who indicated at the end of the survey that they were willing to participate in a 30 minute follow-up individual interview. Although 109 children and adolescents volunteered for a follow-up interview, many disregarded the follow-up e-mail or withdrew without explanation. Five participants initiated contact with the researcher to volunteer for a follow-up interview. Of the five, only three followed through with contact information to schedule an interview appointment at the NAAF conference in St. Louis. The other two participants did not respond to e-mail or a phone call and were removed from the interview list. An additional participant was recruited from the pilot study.

Procedures. The 109 participants who indicated their willingness to volunteer for a follow-up interview were placed in Table 4 according to their age, gender, and duration of AA. The ideal situation would have been to have two male and two female participants represented in each of the age groups (a) 10-13, (b) 14-16, and (c) 17-19 with short duration of AA (1-6 years) and long duration of AA (over 7 years). These groupings closely followed the stages of adolescent development (Spano, 2004) and the frequency-based categories of the quantitative phase of the study. Spano (2004) reports early adolescence to be approximately 10-14 years of age, middle adolescence as 15-16 years of age, and late adolescence as between 17-21 years of age.

The three individuals who had confirmed an interview date and time were highlighted on the table in order to indicate that the category requirement was fulfilled and that the additional participants in those categories were no longer needed. Eight

participants initiated contact with the researcher via e-mail. Four did not respond, so they were excluded from the list. This reduced the number of participants to 77.

Table 4

Follow-up Individual Interview Criteria

Male (2)	Female (2)
Ages 10-13	Ages 10-13
Short Duration of AA (1-6 years) or Long Duration of AA (over 7 years)	Short Duration of AA (1-6 years) or Long Duration of AA (over 7 years)
Male (2)	Female (2)
Ages 14-16	Ages 14-16
Short Duration of AA (1-6 years) or Long Duration of AA (over 7 years)	Short Duration of AA (1-6 years) or Long Duration of AA (over 7 years)
Male (2)	Female (2)
Ages 17-19	Ages 17-19
Short Duration of AA (1-6 years) or Long Duration of AA (over 7 years)	Short Duration of AA (1-6 years) or Long Duration of AA (over 7 years)

The remaining 77 participants were given a number from 01 to 77. Using a table of random numbers, 77 numbers were extracted (Gay, Mills, & Airasian, 2009). As the random numbers in sequence matched the participant number, that participant was given

a number in sequence from 1 through 77. Participants in each category were then contacted in numeric order.

The researcher, via e-mail, began contacting the participants in the order described above to fill all 12 categories. If the e-mail provided was incorrect, by bouncing back, the researcher tried contacting by phone. The researcher provided her location and phone number to all contacts. She also asked if the potential interviewee had access to Skype for the follow-up interview. If volunteers did not respond within one week, they were eliminated from the list. Once the individual confirmed acceptance to be interviewed, he/she was e-mailed once again for an address so that the consent/assent forms could be sent and to set up a date and time convenient to both the interviewee and researcher. The researcher also asked each participant for a location, as the time of the interview needed to be adjusted for time zone differences if the interviewee was not living on the east coast. Several participants were reluctant to give their mailing address, so the appropriate consent/assent forms were scanned and sent to the participants via e-mail. The interview did not take place until the forms were signed and returned. The participants were told that the interview would take about 30 minutes. The individual interviews were audio recorded using a digital voice recorder in addition to a computer audio recorder as a back-up in the event one device would fail to work or to clarify a statement that may be perceived as unclear. Actual names and identifying information were replaced with pseudonyms for the purpose of maintaining confidentiality.

An individual interview guide was prepared in advance and approved by the IRB with pertinent questions to be asked that would relate back to the research questions (see

Appendix M). The protocol also contained a short demographic table asking information similar to what was asked on the survey, as well as a field notes sheet so that observations could be noted during the interview process. Seven open-ended questions were asked to generate additional comments and details regarding the child's or adolescent's experience with AA.

The following qualitative questions were addressed during the follow-up individual interviews intended to clarify and enrich the qualitative findings in more detail. These questions included, but were not limited to, the following:

1. Describe your feelings about having and living with AA?
2. What strategies do you use to cope with your AA?
3. How do other people make you feel about AA?
4. How has AA influenced the type of activities you choose to do? Indoor sports vs. outdoor sports (e.g., sports, fine arts, performing arts, exercise)?
5. What has been the most difficult situation you have had to deal with, with AA? What has been a positive experience you have had?
6. How has your self-perception been impacted by AA? Has there been any change?
7. How has your opinion/experience about having AA changed over time?

Data collection involved the use of audio recording of the individual interviews then transcribing the recording. Field notes were taken regarding how participants reacted to interview questions including body language and facial expressions. In

addition, follow-up e-mail correspondence was used to clarify statements or ask additional questions.

The documentation of phone calls, e-mails, and other correspondence was collected and filed in one of three pocket folders. On the front of the first folder 10-13 was written to indicate the interviews from the 10-13 year olds. The second folder was labeled 14-16 to indicate this age group and the third folder was labeled 17-19 to indicate that particular age group. The inside left pocket of the folders was marked SHORT and the right side was marked LONG to indicate the duration of AA. The interview guide, field notes, transcriptions, consent/assent forms, and e-mails were clipped together and placed in the appropriate folder and pocket. Follow-up thank you notes were sent to the participants for their time during the interview process as well as a small token of appreciation (e.g., sticky notes, novelty key chains, and pens).

Outcomes. The researcher was only able to secure 11 children or adolescents for follow-up interviews out of the intended 12. Three of these individuals were interviewed face-to-face at the NAAF conference and eight were interviewed via Skype. Therefore, the proposed interview categories were not fully realized. Soliciting males was more difficult than females. Females were represented in all three categories. Unfortunately, the male category of 10-13, long duration could not be filled, and the male category of 17-19, short duration could not be filled due to lack of participants or lack of interest as the researcher tried to contact these participants several times unsuccessfully. The researcher then supplemented with interviewing the pilot study participant who volunteered to be interviewed. Participant details are provided in the Results section.

Three older adolescents who initially accepted the invitation to be interviewed were sent the consent forms but later withdrew their acceptance. Three families were sent a scanned version of the consent/assent forms, but did not follow through after an e-mail reminder. Several other volunteers never acknowledged the e-mail invitation. Other potential participants e-mailed back to confirm receipt of the scanned documents but were unable to print out copies to be signed. The consent and assent forms were then converted to a PDF file as another way to access the document.

Qualitative Reliability and Validity

A random numbers chart was used when recruiting volunteers for the follow-up interview. A number was assigned to each volunteer to ensure that any individual had an equal probability of being chosen (Creswell, 2008).

The researcher acknowledges that biases may have influenced comments by participants. She has also lived with AA for over 25 years, was support group leader and met with others with AA on a monthly basis. Managing the reactions of the interviewees to difficult questions was handled with empathy and comments validating their feelings and concerns. A lull in the interview opened an opportunity for the researcher to share a personal story or situation in order to give the participant time to gather their thoughts. As a novice interviewer and an individual with AA, the researcher sought for a comfortable forum for the interview. Interview participants may have over-identified with the researcher due to familiarity with AA (Glesne, 2006) and that a friendship relationship could cause loss of objectivity. However, Glesne suggests that a friendship relationship could help develop new understandings through mutual caring.

Maxwell (2005) recommended using triangulation to manage validity threats by using a variety of data sources. In this mixed-methods study, data was collected from the survey, the transcripts of the audio recordings of the interviews, and the field notes from observations made during the interviews.

Member checks were used to test the credibility of the data (Guba, 1981). Follow-up e-mails and phone calls validated that statements the participants made were accurate. Several participants were e-mailed and asked to verify a statement or add additional information from their interview for clarification.

Also, feedback from others in search of discrepant evidence was also used in order to check biases or flows in the data. The research dissertation chairman was given a copy of the transcripts to verify results (Maxwell, 2005).

Data Analysis

The Statistical Package for the Social Sciences (SPSS) was used for data analysis (Green & Salkind, 2011). The data were collected in two forms, SPSS and Excel. In the first analysis, descriptive statistics and frequency distributions were collected on all the data and were examined to determine percentages, mean scores, and standard deviations (Mertler & Vannatta, 2002). Cronbach's alpha was conducted to assess variability and reliability, results of which were previously noted. An exploratory factor analysis explored if there was a relationship among the variables (Green & Salkind, 2011). T-tests and ANOVA were used to compare means of groups (see Table 5).

Table 5

Data Analysis Summary

Data Analysis	Data Collected	Test
What are the factors that impact children and adolescents with AA?	DV Impact Questions	Factor Analysis
What types of coping strategies are used by children and adolescents with AA?	DV Coping Questions	Factor Analysis
How do the impact factors differ by group (e.g., age, gender, onset, duration)?	IV Questions DV Impact Questions	ANOVA (age, onset) t-test (gender, duration)
How do the types of coping strategies used differ by group (e.g., age, gender, onset, duration)?	IV Questions DV Coping Questions	ANOVA (age, onset) t-test (gender, duration)
Which individual impact items have the greatest and least influence on children and adolescents with AA?	DV Impact Questions	Descriptive
Which types of coping strategies are used most and least frequently by children and adolescents with AA?	DV Coping Questions	Descriptive
How do children and adolescents describe the experience of having AA over time?	Interviews	Coding

Based on the 13 demographic responses, descriptive statistics were used to characterize the participants. Frequency distributions were also used to show the frequency of a category's occurrence in the data set (Green & Salkind, 2011).

Two exploratory factor analyses were completed to determine if every question asked in the survey was essential and whether each related to the other variables (Creswell, 2008). Comrey (1998) suggested that this type of an analysis could be helpful

in developing good scales. Factor analyses eliminate questions that overlap or cluster together and could possibly reduce the number of survey questions due to redundancy (Mertler & Vannatta, 2002). DeVellis (2012) adds that the purpose of a factor analysis is to (a) determine the number of latent variables present in the items, (b) explain variation among variables, which could result in fewer scores to compute, and (c) define the meaning of the factors. An eigenvalue of 1.00 or higher was used and is the common criterion for determining how many factors to retain (Dimitrov, 2012) as it reveals the total variance explained by each factor. Green and Salkind (2011) add that eigenvalues may not always produce accurate results. Therefore, a scree test based on eigenvalues was also completed to identify factors that are nonessential (DeVellis, 2012). The factors were also rotated and sorted by size to make the results easier to interpret and more meaningful (Green & Salkind, 2011). A Kaiser-Meyer-Olkin (KMO) test was also conducted to determine the degree of common variance among the variables (Dimitrov, 2012), and adequacy of the sample. Bartlett's test was also examined for significance. This test determined if factoring the variables was appropriate (Dimitrov, 2012). Comrey (1998) suggested guidelines when creating a scale for research. He used a factor-analytic approach in that the items to be measured must be correlated with each other to stand up to a factor analysis. Tinsley and Tinsley (1987) considered five attributes when assessing data for factor analysis: (a) determine if there are common dimensions within the data; (b) consideration of the sample size; (c) measure of association; (d) dependency of the variables; and (e) meaningful data matrix. The impact factors and types of coping strategies identified were recoded to specify a total score for each factor.

T-tests were used to compare the means of two groups to determine if they are statistically different (Green & Salkind, 2011). Independent-samples t-tests were run on the duration of having AA in relation to the identified impact factors and types of coping strategies used. Duration, the length of time a participant had AA was measured in two groups based on a midpoint split of responses separating short- and long-term diagnosis of AA. This yielded a short duration of between 1-6 years, and a long duration categorized as between 7-17 years. These groupings were re-coded in SPSS prior to analysis. T-tests were also run on gender (e.g., male and female) in relation to the impact factors identified in the factor analysis and the types of coping strategies used. Levene's Test for Equality of Variances was also recorded. It is used to test if items have equal variance. If the p value is less than .05 then equal variance is not assumed (Green & Salkind, 2011). A significance level of $p < 0.05$ was used as the criteria for significance as this is a common probability level used when conducting behavioral research (Mertler & Vannatta, 2002).

The method of analysis of variance (ANOVA) was used to compare the means of three or more groups. ANOVAs were used to compare different categories of a particular independent variable having more than two groups (Dimitrov, 2008). In this study those variables were the comparison of age at the time of the study and the age of onset of AA. These groups were compared to the impact factors and types of coping strategies identified as a result of the factor analyses. The age range was divided into three groups in order to attain balanced representation across groups (e.g., 10-13, 14-16, 17-19). Age of onset responses was compared by three categories as well (e.g., 1-5, 6-10, 11-19).

These groupings were re-coded in SPSS prior to analysis. An F-test was used to compare groups to see if they were statistically different. A significance level of $p < .05$ was used as the criteria for significance as this is a common probability level used when conducting behavioral research (Mertler & Vannatta, 2002).

There were no missing data as the survey was set up so that the participants were required to answer the question in order to move on to the next (Dillman et al., 2009). As mentioned during the national survey discussion, several participants who indicated that they were either younger than 10 or older than 19 were excluded from the study because their scores were outside of the criteria (Creswell, 2008). The data from the national study was screened by visually inspecting the respondents' answers and comparing the SPSS data with the Excel data. Missing data were checked via SPSS and there were no missing values in the data set. Outliers were also checked by charting histograms and running a Mahalanobis Distance for outliers. No outliers were found. The frequencies were collected to determine how often a particular item was noted.

Constant comparative analysis was used to analyze the qualitative data. The data were analyzed by coding the information into themes, which were frequently reviewed until no new themes could be developed (Hewitt-Taylor, 2001). Through open coding the researcher was able to form initial categories regarding what the children and adolescents were sharing about their AA (Creswell, 2008). These categories were placed in an Excel program so that the information could be compiled and organized efficiently. Headings and sub-headings were created. Axial coding was then used to explore connections between the categories and determine how they are related (Creswell, 2008).

Comparing and contrasting was a key component to analyzing the data. This gave the researcher the ability to analyze and reflect not only on new data, but older data as well (Boeije, 2002). Boeije also suggests that comparisons should be made within and between different groups as qualitative research is cyclical. Reviewing and comparing data is only one way of minimizing threats to the validity of the data. From the data, a concept map was created to display relationships between themes and sub-themes (see Figure 1). A concept map is a tool that gives a visible display of what is going on with the phenomenon being studied (Maxwell, 2005).

Summary

This mixed methods study included 237 participants via an online survey focusing on the factors that impact children and adolescents when managing their AA. A 68 question survey was created, validated, and revised. The revised survey contained 56 questions and was piloted with the AA local support group. Subsequently, it was sent, with the assistance of NAAF, to members of their foundation via e-mail, Twitter, and Facebook accounts. The data were then analyzed using SPSS. Table 5 summarizes the research questions and accompanying data analyses. Once the survey data had been collected and analyzed, participants who had volunteered for a follow-up interview were recruited. Interviews were scheduled and were conducted face-to-face in-person or via Skype. The transcripts and field notes from these interviews were ultimately coded and themed. This qualitative data was assessed, compared to, and connected to the data produced by the survey for an in-depth explanation as to the facts that impact children and adolescents with AA and the strategies they use cope with this condition.

4. RESULTS

The purpose of this study is to determine the factors that impact children and adolescents with AA and the type of coping strategies they use in dealing with this condition on a daily basis. The pilot study was reviewed for procedural effectiveness as were previously discussed. The national study utilized the survey and interview protocols to address the following research questions:

1. What are the factors that impact children and adolescents with AA?
2. What types of coping strategies are used by children and adolescents with AA?
3. How do the impact factors differ by group (e.g., age, gender, onset, and duration)?
4. How do the types of coping strategies used differ by group (e.g., age, gender, onset, and duration)?
5. Which individual impact items have the greatest and least influence on children and adolescents with AA?
6. Which types of coping strategies are used most and least frequently by children and adolescents with AA?
7. How do children and adolescents describe the experience of having AA over time?

The analyses included descriptive statistics for all 237 participants, frequency distribution, a factor analysis on both impact factors and types of coping strategies, t-tests, ANOVA analysis, frequency distributions, and qualitative themes and findings.

National Study

The NAAF was able to track and record the data through the survey. This was recorded through a click-through rate explained below. This data was available only from e-mails sent. Response rates from Twitter and Facebook accounts were unavailable.

Click-through Rate. The survey was sent through NAAF to their e-mail database, which includes recipients that fall outside the criteria of this study. Therefore, many people received the e-mail who were not actually targeted and, thereby, did not fill out the survey (See Table 7). Since the target audience of children and adolescents was not readily available, click-through rates give a more representative picture of the targeted population. Click-through rates measure a recipient's interest in an e-mail to click on a link in order to seek further information and increase viewer involvement (Lohtia, Donthu, & Hershberger, 2004).

Table 6

Click-through Response Rate (N = 259)

Recipient Response	Initial e-mail	1 st Follow-up	2 nd Follow-up	Total
Recipient Opens	3,274	1,291	2,770	7,335
Recipient Click-Throughs	286	246	347	879
Forwarded Opens	877	316	756	1,949
Forwarded Click-Throughs	20	16	18	54

Note. Pilot not included

As the chart shows, 9,284 (7,335 + 1,949) recipients opened either through direct or forwarded e-mails. Of those recipients who opened the e-mail, 933 (879 + 54) clicked through and of those, 259 (27.8%) of the click-throughs completed the survey. This could indicate that once the e-mail was opened and the recipients read that the survey criteria included only children and adolescents ages 10–19 years of age; those not meeting the requirements did not continue with the survey. The forwarded opens are the number of people who received the e-mail and opened it from a third party. Forwarded click-throughs denote the number of people who clicked at least one link in the message (Convio, 2013).

Participants

Descriptive statistics, based upon frequency distributions for demographic characteristics, help to characterize the participants. Results can be viewed in Tables 7. Female participants (68%) outnumbered male participants (32%) by two to one and three-quarters of the participants were Caucasian (76%). Only four of the participants indicated that they were not students, and the raw data confirmed that three were 19 year olds and one was 17. Five of the participants (2%) stated that they were in special education. Of these five, two were females ages 10 and 15 while three were males; two were 13 and one was 17. All five had alopecia for most of their lives and all but one indicated that they had been bullied at some point in their life. Forty six percent of all participants indicated that they had been bullied because of their hair loss. Fourteen participants (6%) had to change schools. The participants' regions of residence were scattered throughout the entire U.S. and the majority lived in suburban areas. The

majority of participants (73%) were first diagnosed with AA when they were under 10 years old and most (72%) had not grown their hair back. The data verified a familial connection (21%) that included both immediate family and extended family.

Table 7

Demographic Characteristics of Participants (N = 237)

Characteristics	N	%
Current Age		
10	30	12.7
11	20	8.4
12	29	12.2
13	24	10.1
14	14	5.9
15	34	14.3
16	19	8.0
17	25	10.5
18	19	8.0
19	23	9.7
Gender		
Male	77	32.5
Female	160	67.5
Ethnicity		
Caucasian	180	75.9
African American	12	5.1
Asian American	12	5.1
Hispanic	15	6.3
Other	18	7.6
Student?		
Yes	233	98.3
No	4	1.7
Had to change schools?		
Yes	14	5.9

Characteristics	N	%
No	223	94.1
Placed in special education?		
Yes	5	2.1
No	232	97.9
Having been bullied because of hair loss?		
Yes	109	46.0
No	128	54.0
U.S. region of residence		
Northeast	49	20.7
Southeast	59	24.9
Midwest	50	21.1
Southwest	18	7.6
Rocky Mountain	11	4.6
Pacific	40	16.9
Noncontiguous	10	4.2
Regional location		
Urban	57	24.1
Suburban	136	57.4
Rural	44	18.6
Age of Diagnosis		
1	13	5.5
2	21	8.9
3	22	9.3
4	10	4.2
5	28	11.8
6	16	6.8
7	17	7.2
8	15	6.3
9	13	5.5
10	18	7.6
11	15	6.3
12	7	3.0
13	10	4.2
14	8	3.4

Characteristics	N	%
15	10	4.2
16	3	1.3
17	6	2.5
18	2	.8
19	3	1.3
Current AA status		
Dx with AA – hair has grown back	66	27.8
Dx with AA – hair has not grown back	171	72.2
Family history		
Someone in immediate family has AA	26	11.0
Someone in extended family has AA	25	10.5
I do not know of anyone in my family with AA	186	78.5
Number of years with AA		
1	26	11.0
2	16	6.8
3	18	7.6
4	21	8.9
5	20	8.4
6	15	6.3
7	24	10.1
8	19	8.0
9	12	5.1
10	21	8.9
11	10	4.2
12	14	5.9
13	7	3.0
14	3	1.3
15	8	3.4
16	2	.8
17	1	.4

Research Question 1: What are the Factors that Impact Children and Adolescents with AA?

The purpose of this factor analysis is to establish what factors impact children and adolescents with AA. It was completed to identify the number of items to retain and analyze. Eigenvalues over 1.0 were retained and explain 64% of variance (see Table 8). The items were highly loaded on the first five components. The Scree plot line for the impact factors begins leveling off after the fifth component and would indicate potential items to drop. Based on this information, only five factors should be interpreted and clarified. The impact factors that evolved are shown in Table 9.

The five impact factors were then rotated in order to more accurately fit of the variables in order to name them on the size of their loadings (see Table 10). A .3 loading value was retained for this analysis. This value was obtained by Field (2005). Field suggests that increasing the default value of 0.1 can assist in the interpretation of the data.

Table 8

Eigenvalues and Percentage of Variance Explained by Each Impact Factor

Factor	Initial Eigenvalues			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	11.082	41.046	41.046	4.075	15.093	15.093
2	2.036	7.541	48.578	3.961	14.671	29.765
3	1.789	6.625	55.211	3.953	14.639	44.404
4	1.230	4.556	59.768	3.323	12.308	56.711
5	1.009	3.738	63.506	1.835	6.795	63.506

The five impact factors accounted for 64% of the variable variance and the communalities ranged from .417 to .773. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was a .933 which measures the degree of common variance among the 27 variables. The .933 is high enough to indicate that a factor analysis is appropriate. Bartlett's test was also significant at .000, which is used to test if samples have equal variance (Field, 2005). Table 8 shows the strength of each factor. The first factor accounted for 41% of the variance, whereas, the fifth factor accounted for 3.7% of the variance. When rotated, the percentage of the first factor accounted for 15.1% of the variance and the fifth accounted for 12.3% of the variance. The five identified impact factors and the 27 corresponding questions are shown in Table 9. Only one of the five factors indicated that these children and adolescents were having difficulty managing their AA. The component loadings when rotated by size can be seen in Table 10.

Table 9

Five Identified Impact Factors (N = 27)

Impact Factor 1 (Confidence/Self-Esteem) (N=8)
I can do things as well as my classmates
I get along well with my family
I have many good qualities
I feel that I have the same opportunities as other people
I feel that I am a special person because of my alopecia areata
I think about my positive qualities once a day
I participate in sports with my friends
My teachers accept me for who I am
Impact Factor 2 (Psychological Effects) (N=7)
I often fear being rejected by others because of my hair loss
I often cry about my hair loss
I think about my hair loss daily
People have made fun of me because I am bald
I prefer to do things by myself because of my alopecia areata
I avoid being around people because of my hair loss
Having alopecia areata makes me angry with myself
Impact Factor 3 (Appearance/Acceptance) (N=6)
I would never change the way I look
I have accepted my hair loss
I would like to have a full head of hair (-)
Having alopecia areata does not bother me
I am okay with the way I look
I have continued to live my life as it was before getting alopecia areata
Impact Factor 4 (Socialization) (N=4)
I can make friends easily
I enjoy hanging out at the mall with my friends
I enjoy going out with my friends
I have a hard time making friends (-)
Impact Factor 5 (Communication) (N=2)
I have told my friends about my alopecia areata
I am afraid to tell my friends about my alopecia areata (-)
(-) indicates negative loadings

Table 10

Component Loadings for the Rotated Solution by Size – Impact Factors

	Comp 1	Comp 2	Comp 3	Comp 4	Comp 5
Impact Factor 1 (Confidence/Self-esteem) (N=8)					
I can do things as well as my classmates	.661				
I get along well with my family	.631				
I have many good qualities	.596				
I feel that I have the same opportunities as other people	.577				
I feel that I am a special person because of my alopecia areata	.561				
I think about my positive qualities once a day	.544				
I participate in sports with my friends	.537				
My teachers accept me for who I am	.518				
Impact Factor 2 (Psychological Effects) (N=7)					
I often fear being rejected by others because of my hair loss		.743			
I often cry about my hair loss		.705			
I think about my hair loss daily		.646			
People have made fun of me because I am bald		.611			
I prefer to do things by myself because of my alopecia areata		.607			
I avoid being around people because of my hair loss		.572			
Having alopecia areata makes me angry with myself		.572			

	Comp 1	Comp 2	Comp 3	Comp 4	Comp 5
Impact Factor 3 (Appearance/Acceptance) (N=6)					
I would never change the way I look			.759		
I have accepted my hair loss			.704		
I would like to have a full head of hair			-.685		
Having alopecia areata does not bother me			.683		
I am okay with the way I look			.635		
I have continued to live my life as it was before getting alopecia areata			.412		
Impact Factor 4 (Socialization) (N=4)					
I can make friends easily				.765	
I enjoy hanging out at the mall with my friends				.715	
I enjoy going out with my friends				.690	
I have a hard time making friends				-.664	
Impact Factor 5 (Communication) (N=2)					
I have told my friends about my alopecia areata					.703
I am afraid to tell my friends about my alopecia areata					-.611

Research Question 2: What Types of Coping Strategies are used by Children and Adolescents with AA?

The purpose of this factor analysis is to establish what types of coping strategies children and adolescents use when managing their AA. It was completed to identify the number of items to retain and analyze. Eigenvalues over 1.0 were retained and explain 56% of variance. The items were highly loaded on the first five components. The Scree plot line for the coping strategies begins leveling off after the fifth component. Based on this information, only five coping strategies should be interpreted and clarified (see Table 11). The five types of coping strategies that evolved from this factor analysis are shown in Table 12.

The five types of coping strategies were then rotated in order to more accurately obtain the fit of the items so as to name them on the size of their loadings (see Table 13). A .3 loading value was retained for this analysis as suggested by Field (2005). The five types of coping strategies accounted for 56% of the variable variance and the communalities ranged from .369 to .691. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was a .703 which measures the degree of common variance among the 15 variables and is high enough to indicate that a factor analysis is appropriate. Bartlett's test was also significant at .00.

Component five, however, revealed two items that were not related. The first item, "My family helps support me with my alopecia areata" had a -.752 loading. This item would stand alone in component five. The second item, "I use make-up (eyeliner, eyebrow pencil, etc.) to disguise my hair loss" loaded in both Component two and five,

but more strongly in five. Therefore, a decision was made to place the “make-up” item in the second component category of Cover-up/Avoidance based on the logic of topical alignment.

Table 11

Eigenvalues and Percentage of Variance Explained by Each Type of Coping Strategy

Factor	Initial Eigenvalues			Rotation Sums of Squared Loadings		
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %
1	3.007	20.047	20.047	2.136	14.242	14.242
2	1.775	11.832	31.879	1.740	11.602	25.844
3	1.282	8.545	40.424	1.581	10.537	36.381
4	1.254	8.361	48.785	1.517	10.110	46.492
5	1.034	6.892	55.677	1.378	9.186	55.677

Table 11 shows the strength of each factor. The first factor accounted for 20% of the variance, whereas, the fifth factor accounted for 6.9% of the variance. When rotated, the first factor accounted for 14% of the variance and the fifth accounted for 9.2% of the variance. The five identified coping strategies and the 15 corresponding questions are shown in Table 12. The component loadings when rotated by size can be seen in Table 13.

Table 12

Five Identified Types of Coping Strategies (N = 15)

Coping Strategy 1 (Physiological - medicinal and alternative treatments) (N=5)
<p>I have used prescription creams for my hair loss</p> <p>I have tried different types of shampoos and conditioners for my hair loss</p> <p>I use prescriptions from the doctor to help me feel better about my hair loss</p> <p>I have tried different diets (diary, protein, veggie, meatless) to grow my hair back</p> <p>I have gotten scalp injections for my alopecia areata</p>
Coping Strategy 2 (Cover-up/Avoidance) (N=4)
<p>I wear hairpieces (wigs) all the time</p> <p>I tell people about my alopecia areata if they ask (-)</p> <p>I wear hats/scarves/do-rags/skull caps to disguise my hair loss</p> <p>I use make-up (eyeliner, eyebrow pencil, etc.) to disguise my hair loss</p>
Coping Strategy 3 (Outside Support) (N=3)
<p>I have attended support group meetings</p> <p>My family and I have attended a professional conference</p> <p>I have had individual counseling</p>
Coping Strategy 4 (Social Network) (N=2)
<p>I have looked up information and resources online about alopecia areata</p> <p>I use social network sites to talk to friends about alopecia areata</p>
Coping Strategy 5 (Family Support) (N=1)
<p>My family helps support me with my alopecia areata (-)</p>
(-) indicates negative loadings

Table 13

Component Loadings for the Rotated Solution by Size – Types of Coping Strategies

	Comp 1	Comp 2	Comp 3	Comp 4	Comp 5
Coping Strategy 1 (Physiological - medicinal and alternative treatments) (N=5)					
I have used prescription creams for my hair loss					
I have tried different types of shampoos and conditioners for my hair loss	.775				
I use prescriptions from the doctor to help me feel better about my hair loss	.696				
I have tried different diets (dairy, protein, veggie, meatless) to grow my hair back	.687				
	.424				
I have gotten scalp injections for my alopecia areata	.395				
Coping Strategy 2 (Cover-up/Avoidance) (N=4)					
I wear hairpieces (wigs) all the time		.669			
I tell people about my alopecia areata if they ask		-.659			
I wear hats/scarves/do-rags/skull caps to disguise my hair loss		.597			
I use make-up (eyeliner, eyebrow pencil, etc.) to disguise my hair loss		.358			

	Comp 1	Comp 2	Comp 3	Comp 4	Comp 5
Coping Strategy 3 (Outside Support) (N=3)					
I have attended support group meetings			.813		
My family and I have attended a professional conference			.718		
I have had individual counseling			.462		
Coping Strategy 4 (Social Network) (N=2)					
I have looked up information and resources online about alopecia areata				.765	
I use social network sites to talk to friends about alopecia areata				.740	
Coping Strategy 5 – Family Support (N=1)					
My family helps support me with my alopecia areata					-.752

Research Question 3: How do the Impact Factors Differ by Group (e.g., age, gender, onset, and duration)?

Comparing gender and duration factors. An independent-samples t-test was conducted to determine if there is a significant difference between the five impact factors that affect children and adolescents with AA and categories of gender and duration. The sum of scores for each impact factor was compared by the mean scores of the two groups. While the minimum criteria for significance were set at .05, the most accurate representation of the level of significance is provided. Based on Cronk's (2012) recommendation, the "Equal variances assumed" row was used when examining the significance level.

Gender. When comparing the mean score of males versus females on impact factors, Factor 1 (Confidence/Self-esteem), results were not significantly different ($t(235) = -.418, p = .676$). The mean of the males ($M = 25.77, SD = 3.61$) was not significantly different from the females ($M = 26.00, SD = 4.22$).

Impact Factor 2 (Psychological effects) results were significantly different ($t(235) = -2.188, p < .05$) for males ($M = 15.04, SD = 4.41$) and females ($M = 16.51, SD = 5.05$). These results suggest that females report greater psychological effects in dealing with their AA than do their male counterparts.

The results of Factor 3 (Appearance/Acceptance) were not significantly different by gender ($t(235) = -.719, p = .473$), for males ($M = 16.77, SD = 3.22$) and females ($M = 17.12, SD = 3.68$).

Impact Factor 4 (Socialization) results were significantly different ($t(235) = -3.828, p < .001$), for males ($M = 11.08, SD = 1.45$) and females ($M = 11.81, SD = 1.35$). This suggests that females reported greater socialization effects than did their male counterparts.

Impact Factor 5 (Communication) results showed a significant difference regarding the impact of communication on their condition ($t(235) = -3.409, p < .01$), for males ($M = 5.06, SD = .713$) and females ($M = 5.42, SD = .765$). This suggests that females report a greater impact of communication than did their male counterparts.

A significant difference was found regarding the areas of Psychological effects, Socialization, and Communication. In all cases, female participants reported greater impact of AA. Levene's test for equality of variances only indicated significance in Impact Factor 5 (Communication), which indicates that the variances are significantly different. A summary of the results are shown in Table 14.

Table 14

A Comparison of Gender and the Five Impact Factors

Variable by Group	M	SD	<i>t</i>	<i>p</i>
Impact Factor 1 (Confidence/Self-Esteem)			-.418	.676
Male	25.77	3.61		
Female	26.00	4.22		
Impact Factor 2 (Psychological Effects)			-2.188	.030
Male	15.04	4.41		
Female	16.51	5.05		
Impact Factor 3 (Appearance/Acceptance)			-.719	.473
Male	16.77	3.22		
Female	17.12	3.68		
Impact Factor 4 (Socialization)			-3.828	.000
Male	11.08	1.45		
Female	11.81	1.35		
Impact Factor 5 (Communication)			-3.409	.001
Male	5.06	.713		
Female	5.42	.765		

Duration. Duration was defined as having AA for a short period of time (1-6 years), or a long period of time (over 7 years). No significant difference was found for Impact Factor 1 (Confidence/Self-Esteem) results relative to duration of AA, ($t(235) = -.135, p = .893$). The mean of short duration ($M = 25.89, SD = 3.93$) was not significantly different from the mean of long duration ($M = 25.96, SD = 4.12$).

A comparison of Impact Factor 2 (Psychological Effects) scores did not result in a significant difference by duration ($t(235) = .798, p = .426$). The mean of short duration

($M = 16.29$, $SD = 4.80$) was not significantly different from the mean of long duration ($M = 15.79$, $SD = 4.99$).

The results of Impact Factor 3 (Appearance/Acceptance) responses also did not result in a significant difference by duration ($t(235) = .423$, $p = .673$). The mean of participants with short duration ($M = 17.10$, $SD = 3.36$) was not significantly different from the mean of those with long duration ($M = 16.91$, $SD = 3.70$).

Duration and Impact Factor 4 (Socialization) did not result in a significant difference ($t(235) = -.507$, $p = .612$). The mean of short duration ($M = 11.53$, $SD = 1.37$) was not significantly different from the mean of long duration ($M = 11.62$, $SD = 1.48$).

Impact Factor 5 (Communication) also did not yield a significant result ($t(235) = 1.49$, $p = .137$) by duration. The mean of short duration ($M = 5.38$, $SD = .820$) was not significantly different from the mean of long duration ($M = 5.23$, $SD = .704$).

A summary of the results is shown in Table 15. None of the comparisons showed a significant difference. Levene's test of equality of variances was not significant on any factor indicating homogeneity of variance. There is no difference in how children and adolescents are impacted by AA whether they have had it for a short or long duration. In two cases, those with longer duration reported slightly greater impact (Confidence/Self-esteem, Socialization); in the other three cases, those with shorter duration reported greater impact (Psychological Effects, Appearance/Acceptance, and Communication). As with gender, the greatest variation in response was in the area of Psychological Effect and the least was in Communication.

Table 15

A Comparison of Duration and the Five Impact Factors

Variable by Group	M	SD	<i>t</i>	<i>p</i>
Impact Factor 1 (Confidence/Self-Esteem)			-.135	.893
Short Duration	25.89	3.93		
Long Duration	25.96	4.12		
Impact Factor 2 (Psychological Effects)			.798	.426
Short Duration	16.29	4.80		
Long Duration	15.79	4.99		
Impact Factor 3 (Appearance/Acceptance)			.423	.673
Short Duration	17.10	3.36		
Long Duration	16.91	3.70		
Impact Factor 4 (Socialization)			-.507	.612
Short Duration	11.52	1.37		
Long Duration	11.62	1.48		
Impact Factor 5 (Communication)			1.492	.137
Short Duration	5.38	.820		
Long Duration	5.23	.704		

Comparing age and onset with impact factors. A one-way ANOVA was conducted comparing the means of three age groups and onset of AA with each of the five impact factors identified in the factor analysis (Cronk, 2012). The age groups consist of younger (10-13), mid (14-16) and older (17-19) children and adolescents. The onset refers to participants diagnosed at a younger age (1-5), mid age (6-10), and older age (11-19). The ANOVA results for age groups are presented in Table 16 and onset in Table 21. Although the minimum criteria for significance were set at .05, the most accurate

representation of the level of significance is provided. Tukey's HSD was used as the post-hoc test of choice for multiple comparisons as recommended by Cronk (2012).

Age. A significant difference for age was found for Impact Factor 1 (Confidence/Self-Esteem) ($F(2, 234) = 12.076, p < .001$). Tukey's HSD was used to determine the nature of the differences between the age groups. This analysis revealed that the youngest group ($M = 27.31, SD = 3.40$) revealed a higher level of confidence and self-esteem than the mid aged ($M = 25.09, SD = 4.22$) and older aged ($M = 24.63, SD = 4.09$) participants. There was no significance between the mid aged group and older aged group (see Table 16).

Table 16

ANOVA Age Group Comparisons of Impact Factor 1 (Confidence/Self-Esteem)

Age Group	N	M	SD	Sig.
Young 10-13	103	27.31	3.40	.001
Mid 14-16	67	25.09	4.22	
Young 10-13	103	27.31	3.40	.000
Old 17-19	67	24.63	4.09	
Mid 14-16	67	25.09	4.22	.766
Old 17-19	67	24.63	4.09	

Impact Factor 2 (Psychological Effects) data was compared with the three age groups and revealed a significant difference ($F(2, 234) = 6.942, p < .01$) between the youngest ($M = 14.87, SD = 4.34$) and older group ($M = 17.66, SD = 5.08$). These results indicate that the older participants were affected more, psychologically, than the younger

participants with AA. The mid-age group ($M = 16.19$, $SD = 5.09$) was not significantly different from either of the other two groups (see Table 17).

Table 17

ANOVA Age Group Comparisons of Impact Factor 2 (Psychological Effects)

Age Group	N	M	SD	Sig.
Young 10-13	103	14.87	4.34	.185
Mid 14-16	67	16.19	5.09	
Young 10-13	103	14.87	4.34	.001
Old 17-19	67	17.66	5.08	
Mid 14-16	67	16.19	5.09	.181
Old 17-19	67	17.66	5.08	

Impact Factor 3 (Appearance/Acceptance) results were significantly different ($F(2, 234) = 10.523$, $p < .001$) for the younger group and both mid and older groups. Results from Tukey's HSD revealed that the young group ($M = 18.10$, $SD = 3.35$) was more accepting of their appearance than both the mid ($M = 16.60$, $SD = 3.25$) and older ($M = 15.73$, $SD = 3.61$) groups. No significant difference was found between the mid and older groups (see Table 18).

Table 18

ANOVA Age Group Comparisons of Impact Factor3 (Appearance/Acceptance)

Age Group	N	M	SD	Sig.
Young 10-13	103	18.10	3.35	.015
Mid 14-16	67	16.60	3.25	
Young 10-13	103	18.10	3.35	.000
Old 17-19	67	15.37	3.61	
Mid 14-16	67	16.60	3.25	.305
Old 17-19	67	15.73	3.61	

No significant difference was found when comparing Impact Factor 4 (Socialization) scores by age groups ($F(2, 234) = .678, p = .509$). The participants in all three age groups did not differ significantly in their reporting of the effect of Socialization on them due to AA. The mean of the younger group was ($M = 11.63, SD = 1.20$), mid ($M = 11.66, SD = 1.52$), and older ($M = 11.57, SD = 1.63$) (see Table 19).

Table 19

ANOVA Age Group Comparisons of Impact Factor 4 (Socialization)

Age Group	N	M	SD	Sig.
Young 10-13	103	11.63	1.20	.993
Mid 14-16	67	11.66	1.52	
Young 10-13	103	11.63	1.20	.565
Old 17-19	67	11.57	1.42	
Mid 14-16	67	11.66	1.52	.558
Old 17-19	67	11.57	1.42	

No significant difference was found when comparing Impact Factor 5 (Communication) scores by age groups ($F(2, 234) = .660, p = .518$). The participants in all three age groups did not differ significantly in how they reported the impact of communicating with others about their AA. The mean of the younger group was ($M = 5.29, SD = .666$), mid ($M = 5.24, SD = .955$), and older ($M = 5.39, SD = .695$).

Table 20

ANOVA Age Group Comparisons of Impact Factor 5 (Communication)

Age Group	N	M	SD	Sig.
Young 10-13	103	5.29	.666	.900
Mid 14-16	67	5.24	.955	
Young 10-13	103	5.29	.666	.700
Old 17-19	67	5.30	.695	
Mid 14-16	67	5.24	.955	.498
Old 17-19	67	5.30	.695	

The one-way analysis of variance was conducted to investigate the comparisons between age groups on the impact factors. A summary of the results are presented in Table 21. There was significance between factors for Impact Factor 1 (Confidence/Self-Esteem), 2 (Psychological Effects), and 3 (Appearance/Acceptance). Levene's Test of Equality evaluated the assumption that the variances for the groups are equal (Green & Salkind, 2011). It was only significant regarding Impact Factor 5 (Communication) which indicates equal variance is not assumed.

Table 21

ANOVA Summary Table of Age Groups and Impact Factors

Factor	SS	df	MS	F	Sig.
1 (Confidence/Self-Esteem)					
Between Groups	357.440	2	178.720	12.076	.000
Within Groups	3463.193	234	14.800		
2 (Psychological Effects)					
Between Groups	316.789	2	158.394	6.942	.001
Within Groups	5338.941	234	22.816		
3 (Appearance/Acceptance)					
Between Groups	242.683	2	121.342	10.523	.000
Within Groups	2698.313	234	11.531		
4 (Socialization)					
Between Groups	2.753	2	1.377	.678	.509
Within Groups	475.204	234	2.031		
5 (Communication)					
Between Groups	.775	2	.387	.660	.518
Within Groups	137.352	234	.587		

Onset. A significant difference was found when comparing Impact Factor 1 (Confidence/Self-Esteem) relative to the onset of AA ($F(2, 234) = 4.691, p < .01$). Using Tukey's HSD, the results indicate that the earlier onset ($M = 26.66, SD = 4.16$) and older ($M = 24.70, SD = 4.22$) onset groups were significantly different from each other. No significance was found between the mid onset group ($M = 26.04, SD = 3.48$) with the earlier or older onset groups. This would indicate that the earlier onset group had more confidence and higher self-esteem than those acquiring AA at an older age (see Table 22).

Table 22

ANOVA Onset Comparisons of Impact Factor 1 (Confidence/Self-Esteem)

Onset Group	N	M	SD	Sig.
Early 1-5	94	26.66	4.16	.560
Mid 6-10	79	26.04	3.48	
Early 1-5	94	26.66	4.16	.007
Older 11-19	64	24.70	4.22	
Mid 6-10	79	26.04	3.48	.114
Older 11-19	64	24.70	4.22	

Responses for Impact Factor 2 (Psychological Effects) relative to age of onset were significant significantly different ($F(2, 234) = 7.633, p < .01$). The results indicate a significant difference between participants with early onset ($M = 15.20, SD = 4.79$) and those with later onset ($M = 18.02, SD = 4.65$). Similarly, participants with mid onset ($M = 15.42, SD = 4.82$) were also significantly different for those with an older age onset. No significant difference was found between early onset and mid age onset. This would suggest that dealing with the psychological effects of AA was more difficult with onset later in life (see Table 23).

Table 23

ANOVA Onset Comparisons of Impact Factor 2 (Psychological Effects)

Onset Group	N	M	SD	Sig.
Early 1-5	94	15.20	4.79	.953
Mid 6-10	79	15.42	4.82	
Early 1-5	94	15.20	4.70	.001
Older 11-19	64	18.02	4.65	
Mid 6-10	79	15.42	4.82	.004
Older 11-19	64	18.02	4.65	

Exploring Impact Factor 3 (Appearance/Acceptance) based upon onset did not result in a significant difference ($F(2, 234) = 2.924, p = .056$), which is just about the minimum significant criteria of .05. A significant difference was found between early onset ($M = 17.57, SD = 3.45$) and older onset ($M = 16.20, SD = 3.77$). No Significant difference was found between the early or older age onset and the mid age onset group ($M = 16.97, SD = 3.33$). This would suggest that participants with an early onset of AA were more positive about their appearance and acceptance of their condition than those who acquired it later in life (see Table 24).

Table 24

ANOVA Onset Comparisons of Impact Factor 3 (Appearance/Acceptance)

Onset Group	N	M	SD	Sig.
Early 1-5	94	17.57	3.45	.501
Mid 6-10	79	16.97	3.33	
Early 1-5	94	17.57	3.45	.043
Older 11-19	64	16.20	3.77	
Mid 6-10	79	16.97	3.33	.391
Older 11-19	64	16.20	3.77	

No significant difference was found when comparing the sum of scores for Impact Factor 4 (Socialization) relative to age of onset of AA ($F(2, 234) = .861, p = .424$). The three onset groups of early ($M = 11.72, SD = 1.38$), mid ($M = 11.48, SD = 1.36$), and older ($M = 11.47, SD = 1.56$) did not differ significantly, which indicates no difference in the effect of socialization relative to age of onset (see Table 25).

Table 25

ANOVA Onset Comparisons of Impact Factor 4 (Socialization)

Onset Group	N	M	SD	Sig.
Early 1-5	94	11.72	1.38	.506
Mid 6-10	79	11.48	1.36	
Early 1-5	94	11.72	1.38	.513
Older 11-19	64	11.47	1.56	
Mid 6-10	79	11.48	1.36	.999
Older 11-19	64	11.47	1.56	

The three age of onset groups in comparison relative to Impact Factor 5 (Communication) also did not produce significant differences ($F(2, 234) = 1.718$, $p = .182$). The mean of the early onset ($M = 5.23$, $SD = .710$), mid onset ($M = 5.27$, $SD = .843$), and older onset ($M = 5.45$, $SD = .733$) did not differ significantly which indicates no difference in the effect of communication relative to age of onset.

Table 26

ANOVA Onset Comparisons of Impact Factor 5 (Communication)

Onset Group	N	M	SD	Sig.
Early 1-5	94	5.23	.710	.960
Mid 6-10	79	5.27	.843	
Early 1-5	94	5.23	.710	.181
Older 11-19	64	5.45	.733	
Mid 6-10	79	5.27	.843	.312
Older 11-19	64	5.45	.733	

The one-way analysis of variance was conducted to investigate the comparisons between the onset of AA on the impact factors. A summary of the results are presented in Table 27. There was significance between factors for Impact Factor 1 (Confidence/Self-Esteem), 2 (Psychological Effects), and 3 (Appearance/Acceptance). Levene's Test of Equality evaluated the assumption that the variances for the groups are equal (Green & Salkind, 2011). This test was not significant, which indicates equal variances.

Table 27

ANOVA Summary Table of Onset and Impact Factors

Factor	SS	df	MS	F	Sig.
1 (Confidence/Self-Esteem)					
Between Groups	147.281	2	73.641	4.691	.010
Within Groups	3673.352	234	15.698		
2 (Psychological Effects)					
Between Groups	346.371	2	173.185	7.633	.001
Within Groups	5309.359	234	22.690		
3 (Appearance/Acceptance)					
Between Groups	71.708	2	35.854	2.924	.056
Within Groups	2869.287	234	12.262		
4 (Socialization)					
Between Groups	3.490	2	1.745	.861	.424
Within Group	474.468	234	2.028		
5 (Communication)					
Between Groups	1.998	2	.999	1.718	.182
Within Groups	136.128	234	.582		

Research Question 4: How do the Types of Coping Strategies used Differ by Group (e.g., age, gender, onset, and duration)?

Comparing gender and duration with types of coping strategies. An independent-samples t-test was conducted to determine if there is a significant difference between the five types of coping strategies that affect children and adolescents with AA and categories of gender and duration. The sum of scores for each type of coping strategy was compared by the mean scores of the two groups. While the minimum

criteria for significance were set at .05, the most accurate representation of the level of significance is provided.

Gender. The means scores based on gender regarding coping strategies revealed no significant difference for males and females for Type of Coping Strategy 1 (Physiological - medicinal and alternative treatments) ($t(235) = -1.140, p = .255$). The mean of the males ($M = 10.75, SD = 3.38$) was not significantly different from the females ($M = 11.30, SD = 3.49$).

Type of Coping Strategy 2 (Cover-up/avoidance) results were significantly different ($t(235) = -5.076, p < .001$) for males ($M = 8.44, SD = 1.68$) and females ($M = 9.91, SD = 2.26$). This suggests that females reported using various types of cover-ups more than their male counterparts.

Type of Coping Strategy 3 (Outside Support) results were not significantly different by gender ($t(235) = -1.216, p = .225$). The means of the males ($M = 5.55, SD = 1.97$) was not significantly different from the mean of the females ($M = 5.89, SD = 2.11$).

Type of Coping Strategy 4 (Social Network) results were significantly different ($t(235) = -3.639, p < .001$) for males ($M = 4.61, SD = 1.37$) and females ($M = 5.35, SD = 1.51$). These results suggest that females reported using social networking more than their male counterparts when dealing with their AA.

Type of Coping Strategy 5 (Family Support) results were not significantly different ($t(235) = .112, p > .911$) for males ($M = 3.71, SD = .509$) and females ($M = 3.71, SD = .521$).

A summary of the results is shown in Table 28. Two types of coping strategies showed a significant difference. Variance in responses was greatest for Type of Coping Strategy 2 (Cover-up/avoidance) and Type of Coping Strategy 4 (Social Network) and least for Type of Coping Strategy 5 (Family Support). Levene's test for equality of variances only indicated significance in Coping Strategy 2 (Cover-up/Avoidance), which indicates that the variances are significantly different.

Table 28

A Comparison of Gender and Type of Coping Strategy

Variable by Group	M	SD	<i>t</i>	<i>p</i>
Type of Coping Strategy 1 (Physiological)				
Male	10.75	3.38	-1.140	.255
Female	11.30	3.49		
Type of Coping Strategy 2 (Cover-up/Avoidance)				
Male	8.44	1.68	-5.076	.000
Female	9.91	2.26		
Type of Coping Strategy 3 (Outside Support)				
Male	5.56	1.97	-1.216	.225
Female	5.89	2.11		
Type of Coping Strategy 4 (Social Network)				
Male	4.61	1.37	-3.639	.000
Female	5.35	1.51		
Type of Coping Strategy 5 (Family Support)				
Male	3.71	.509	.112	.911
Female	3.71	.521		

Duration. The five types of coping strategies were compared to duration of AA. To reiterate, short duration is defined as having AA for 1 to 6 years, or a long duration of over 7 years. A comparison of Type of Coping Strategy 1 (Physiological) scores resulted

in a significant difference ($t(235) = 3.049, p < .05$). The mean of short duration ($M = 11.81, SD = 3.14$) was higher than the mean of the long duration ($M = 10.46, SD = 3.63$). This suggests that newly diagnosed children and adolescents are more likely to use treatment measures to grow their hair back.

Type of Coping Strategy 2 (Cover-up/Avoidance) did not yield a significant result ($t(235) = .685, p = .494$). The mean of short duration ($M = 9.53, SD = 2.05$) was not significantly different from the mean of long duration ($M = 9.34, SD = 2.33$).

The results of Type of Coping Strategy 3 (Outside Support) responses did not result in a significant difference ($t(235) = .028, p = .977$). The mean of the short duration ($M = 5.78, SD = 2.15$) and the mean of the long duration ($M = 5.78, SD = 1.99$) were not significant.

Type of Coping Strategy 4 (Social Network) was also not significant ($t(235) = .715, p = .476$). The mean for short duration ($M = 5.18, SD = 1.56$) was not significantly different from long duration ($M = 5.04, SD = 1.45$).

In addition, Type of Coping Strategy 5 (Family Support) did not reflect a significant difference ($t(235) = -.057, p = .954$). The mean for short duration ($M = 3.71, SD = .528$) was not significantly different from long duration ($M = 3.71, SD = .507$). Type of Coping Strategy 1 (Physiological) was the only strategy that produced a significant difference. Levene's test for equality of variances did not indicate any significant differences. A comparison of the Types of Coping Strategies and duration can be seen in Table 29.

Table 29

A Comparison of Duration and Type of Coping Strategy

Variable by Group	M	SD	<i>t</i>	<i>p</i>
Coping Strategy 1 (Physiological)			3.049	.002
Short Duration	11.81	3.14		
Long Duration	10.46	3.63		
Coping Strategy 2 (Cover-up/Avoidance)			.685	.494
Short Duration	9.53	2.05		
Long Duration	9.34	2.33		
Coping Strategy 3 (Outside Support)			.028	.977
Short Duration	5.78	2.15		
Long Duration	5.78	1.99		
Coping Strategy 4 (Social Network)			.715	.476
Short Duration	5.18	1.56		
Long Duration	5.04	1.45		
Coping Strategy 5 (Family Support)			-.057	.954
Short Duration	3.71	.528		
Long Duration	3.71	.507		

Comparing age and onset with types of coping strategies. A one-way ANOVA was conducted comparing the three age groups and onset of AA with each of the five types of coping strategies identified in the factor analysis. The age groups consist of younger (10-13), mid (14-16) and older (17-19) children and adolescents. The onset refers to participants diagnosed at a younger age (1-5), mid age (6-10), and older age (11-19). While the minimum criteria for significance were set at .05, the most accurate representation of the level of significance is provided.

Age. A significant difference for age was found for Type of Coping Strategy 1 (Physiological - medicinal and alternative treatments) ($F(2, 234) = 10.184, p < .001$). Tukey's HSD was used to determine the nature of the differences between the age

groups. This analysis revealed a significant difference between younger ($M = 10.29$, $SD = 3.41$) and older ($M = 12.63$, $SD = 3.35$), as well as younger and mid aged ($M = 10.90$, $SD = 3.18$) groups. The results indicated that the mid and older participants tended to use treatments more readily than the younger aged group (see Table 30).

Table 30

ANOVA Age Group Comparisons to Type of Coping Strategy 1 (Physiological)

Age Group	N	M	SD	Sig.
Young 10-13	103	10.41	3.41	.481
Mid 14-16	67	10.90	3.18	
Young 10-13	103	10.41	3.41	.000
Old 17-19	67	12.63	3.35	
Mid 14-16	67	10.90	3.18	.008
Old 17-19	67	12.63	3.35	

Type of Coping Strategy 2 (Cover-up/Avoidance) results were significantly different for age ($F(2, 234) = 15.434$, $p < .001$). Results from Tukey's HSD confirmed a significant difference between the younger age group ($M = 8.66$, $SD = 1.89$) and older age group ($M = 10.45$, $SD = 2.20$). A significant difference was also found between the younger age group and the mid age group ($M = 9.611$, $SD = 2.21$). No significant difference was found between the mid age group and the older age group. This would indicate that the older participants were more likely than the younger participants to use cover-up strategies in order to conceal their hair loss (see Table 31).

Table 31

ANOVA Age Group Comparisons to Type of Coping Strategy 2 (Cover-up/Avoidance)

Age Group	N	M	SD	Sig.
Young 10-13	103	8.66	1.89	.011
Mid 14-16	67	9.61	2.21	
Young 10-13	103	8.66	1.89	.000
Old 17-19	67	10.45	2.20	
Mid 14-16	67	9.61	2.21	.053
Old 17-19	67	10.45	2.20	

Type of Coping Strategy 3 (Outside Support) results were significantly different for age ($F(2, 234) = 4.451, p < .05$) for the younger age group ($M = 6.22, SD = 2.06$) and the mid age group ($M = 5.34, SD = 1.98$). There was no significant difference between the younger and older aged group ($M = 5.54, SD = 2.05$) or between the mid and older aged group. The younger participants ages 10 to 16 reported using more outside supports to help them deal with their AA than the older age group (see Table 32).

Table 32

ANOVA Age Group Comparisons to Type of Coping Strategy 3 (Outside Support)

Age Group	N	M	SD	Sig.
Young 10-13	103	6.22	2.06	.018
Mid 14-16	67	5.34	1.98	
Young 10-13	103	6.22	2.06	.083
Old 17-19	67	5.54	2.05	
Mid 14-16	67	5.34	1.98	.846
Old 17-19	67	5.54	2.05	

The comparison of the three age groups with Type of Coping Strategy 4 (Social Network) revealed a significant difference ($F(2, 234) = 12.326, p < .001$). Tukey's HSD found a significant difference between the younger age ($M = 4.58, SD = 1.38$) with both mid age ($M = 5.55, SD = 1.60$) and older age groups ($M = 5.48, SD = 1.34$). No significant difference was found between the mid and older age groups. The mid aged group reported using social networking more than the younger age group (see Table 33).

Table 33

ANOVA Age Group Comparisons to Type of Coping Strategy 4 (Social Network)

Age Group	N	M	SD	Sig.
Young 10-13	103	4.58	1.38	.000
Mid 14-16	67	5.55	1.60	
Young 10-13	103	4.58	1.38	.000
Old 17-19	67	5.48	1.34	
Mid 14-16	67	5.55	1.60	.951
Old 17-19	67	5.48	1.34	

Type of Coping Strategy 5 (Family Support) results were also significantly different for age groups ($F(2, 234) = 3.289, p < .05$). However, Tukey's HSD did not produce any significant differences between age groups. The mean for the younger age group ($M = 3.81, SD = .466$), mid age group ($M = 3.63, SD = .487$), and older age group ($M = 3.64, SD = .595$). Table 34 shows the lack of significant differences in paired comparisons, while Table 35 reports the significant differences between groups.

Table 34

ANOVA Age Group Comparisons to Type of Coping Strategy 5 (Family Support)

Age Group	N	M	SD	Sig.
Young 10-13	103	3.81	.466	.068
Mid 14-16	67	3.63	.487	
Young 10-13	103	3.81	.466	.104
Old 17-19	67	3.64	.595	
Mid 14-16	67	3.63	.487	.984
Old 17-19	67	3.64	.595	

All comparisons between age groups and Types of Coping Strategies yielded significant results. All age groups utilized some type of coping strategy in helping them manage their AA. Levene's test for equality of variances only indicated significance for Type of Coping Strategy 5 (Family Support) which concludes that variances are significantly different. See Table 35 for a summary of results.

Table 35

ANOVA Summary Table of Age and Type of Coping Strategy

Strategy	SS	df	MS	F	Sig.
1. (Physiological)					
Between Groups	226.249	2	113.125	10.184	.000
Within Groups	2599.202	234	11.108		
2 (Cover-up/Avoidance)					
Between Groups	132.652	2	66.326	15.434	.000
Within Groups	1005.584	234	4.297		
3 (Outside Support)					
Between Groups	39.965	2	18.483	4.451	.013
Within Groups	971.625	234	4.152		
4 (Social Network)					
Between Groups	50.816	2	25.408	12.326	.000
Within Group	482.332	234	2.061		
5 (Family Support)					
Between Groups	1.720	2	.860	3.289	.039
Within Groups	61.191	234	.262		

Onset. A significant difference was found when comparing Type of Coping Strategy 1 (Physiological - medicinal and alternative treatments) relative to the onset of AA ($F(2, 234) = 12.384, p < .001$). Using Tukey's HSD the results indicate a significant difference between the earlier onset ($M = 9.85, SD = 3.37$) and both the mid onset ($M = 11.63, SD = 3.64$) and older onset ($M = 12.36, SD = 2.72$). No significant difference was found between the mid onset and older aged onset. This would indicate that participants who developed AA when they were older reported a greater use of medicinal and alternative treatments than their younger counterparts (see Table 36).

Table 36

ANOVA Onset Comparisons to Type of Coping Strategy 1 (Physiological)

Onset Group	N	M	SD	Sig.
Early 1-5	94	9.85	3.37	.001
Mid 6-10	79	11.63	3.64	
Early 1-5	94	9.85	3.37	.000
Older 11-19	64	12.36	2.72	
Mid 6-10	79	11.63	3.64	.393
Older 11-19	64	12.36	2.72	

Responses for Type of Coping Strategy 2 (Cover-up/Avoidance) relative to age of onset were significantly different ($F(2, 234) = 5.624, p < .01$). The results indicate a significant difference for earlier onset ($M = 8.99, SD 2.16$) and older onset ($M = 10.16, SD = 1.94$). No significant difference was found for early onset and mid onset ($M = 9.38, SD = 2.31$) or for mid onset and older onset of AA. This would suggest that participants developing AA later in life tend to use cover-up more often than those who developed AA early on in life (see Table 37).

Table 37

ANOVA Onset Comparisons to Type of Coping Strategy 2 (Cover-up/Avoidance)

Onset Group	N	M	SD	Sig.
Early 1-5	94	8.99	2.16	.462
Mid 6-10	79	9.38	2.31	
Early 1-5	94	8.99	2.16	.003
Older 11-19	64	10.16	1.94	
Mid 6-10	79	9.38	2.31	.083
Older 11-19	64	10.16	1.94	

No significant difference was found when comparing the sum of scores for Coping Strategy 3 (Outside Support) relative to onset of AA ($F(2, 234) = 1.648$, $p = .195$). The three groups did not differ significantly. Early onset ($M = 6.01$, $SD = 2.10$), mid onset ($M = 5.81$, $SD = 2.11$), and older onset ($M = 5.41$, $SD = 1.95$) (see Table 38).

Table 38

ANOVA Onset Comparisons to Type of Coping Strategy 3 (Outside Support)

Onset Group	N	M	SD	Sig.
Early 1-5	94	6.01	2.10	.800
Mid 6-10	79	5.81	2.11	
Early 1-5	94	6.01	2.10	.169
Older 11-19	64	5.41	1.95	
Mid 6-10	79	5.81	2.11	.475
Older 11-19	64	5.41	1.95	

A significant difference was found comparing Coping Strategy 4 – Social Network relative to age of onset ($F(2, 234) = 9.087, p < .001$). Using Tukey's HSD, the results indicate that earlier onset ($M = 4.93, SD = 1.44$) and older onset ($M = 5.77, SD = 1.28$) groups were significantly different from each other and mid onset ($M = 4.80, SD = 1.60$) and older onset were also significantly different. No significance was found between earlier onset and mid onset. This would suggest that participants who develop AA later in life report using social networking more often to look up information and resources about AA and to connect with others with AA (see Table 39).

Table 39

ANOVA Onset Comparisons to Type of Coping Strategy 4 (Social Network)

Onset Group	N	M	SD	Sig.
Early 1-5	94	4.93	1.44	.833
Mid 6-10	79	4.80	1.60	
Early 1-5	94	4.93	1.44	.001
Older 11-19	64	5.77	1.28	
Mid 6-10	79	4.80	1.60	.000
Older 11-19	64	5.77	1.28	

A significant difference was also found comparing Coping Strategy 5 (Family Support) relative to age of onset ($F(2, 234) = 3.218, p < .05$). These results indicate a significant difference for earlier onset ($M = 3.79, SD = .411$) and older onset ($M = 3.58, SD = .586$). No significant difference was found for early onset and mid onset

($M = 3.72$, $SD = .553$) or mid onset and older onset. This suggests that the earlier onset participants relied more on family support than those diagnosed later in life (see Table 40).

Table 40

ANOVA Onset Comparisons to Type of Coping Strategy 5 (Family Support)

Onset Group	N	M	SD	Sig.
Early 1-5	94	3.79	.411	.677
Mid 6-10	79	3.72	.553	
Early 1-5	94	3.79	.411	.033
Older 11-19	64	3.58	.586	
Mid 6-10	79	3.72	.553	.220
Older 11-19	64	3.58	.586	

The one-way analysis of variance was conducted to investigate the comparisons between onset of AA and types of coping strategies. A summary of the results can be seen in Table 41. There was significance between all but one type of coping strategy. Type of Coping Strategy 3 (Outside Support) is a strategy not often utilized by children and adolescents. Levene's test for equality of variances indicated significance for Type of Coping Strategy 1 (Physiological) and Type of Coping Strategy 5 (Family Support), which indicates that the variances are significantly different.

Table 41

ANOVA Summary Table of Onset and Type of Coping Strategy

Strategy	SS	df	MS	F	Sig.
1 (Physiological)					
Between Groups	270.448	2	135.224	12.384	.000
Within Groups	2555.004	234	10.919		
2 (Cover-up/Avoidance)					
Between Groups	52.202 1086.034	2	26.101	5.624	.004
Within Groups		234	4.641		
3 (Outside Support)					
Between Groups	14.012	2	7.006	1.648	.195
Within Groups	994.579	234	4.250		
4 (Social Network)					
Between Groups	38.425	2	19.213	9.087	.000
Within Group	494.723	234	2.114		
5 (Family Support)					
Between Groups	1.684	2	.842	3.218	.042
Within Groups	61.227	234	.262		

Research Question 5: Which Individual Impact Items have the Greatest and Least Influence on Children and Adolescents with AA?

The data were examined by conducting a descriptive analysis. The strongly disagree and disagree responses were added to indicate one percentage on the disagree end of the Likert-type scale and the strongly agree and agree responses were added together to specify one percentage on the agree end of the scale (see Table 42). Eight questions (12, 15, 17, 21, 26, 29, 33, 36) were reverse coded.

The majority of the participants responded positively to Impact Factor 1 (Confidence/Self-Esteem) items about how they were dealing with their AA. They felt that they got along well with their family (96%), felt accepted by their teachers (96%),

were able to perform as well as classmates (95%), had many admirable qualities (95%), had the same opportunities as others (86%), participated in sports with friends (79%), and thought about their positive qualities daily (67%). While the lowest score was still a majority of respondents, 54% of participants felt they were a special person because of their hair loss.

Impact Factor 2 (Psychological Effects) had an impact on the children and adolescents in this study. Most avoided being around people (81%), preferred to do things alone (74%), felt angry with themselves for having AA (73%), often cried about their hair loss (67%), had been made fun of because of their hair loss (62%), and feared being rejected by others (53%). However, only 38% of the respondents indicated that they thought about their hair loss daily.

Impact Factor 3 (Appearance/Acceptance) results indicated that most participants continued to live their life as it was before AA (79%), had accepted their hair loss (72%), and were okay with the way they looked (66%). However, the majority would like to change the way they look (57%) and would like to have a full head of hair (89%) and disclosed that having AA does bother them (66%).

Impact Factor 4 (Socialization) revealed that, again, the majority of participants enjoyed just going out with friends (95%), made friends easily (84%), enjoyed hanging out at the mall with friends (75%). However, 81% also indicated they had a hard time making friends.

Impact Factor 5 (Communication) revealed that although most children and adolescents told their friends about their AA (86%), they were also hesitant to mention the subject as well (67%).

Scores of 90% and above were found primarily in Impact Factor 1 (Confidence/Self-Esteem) with an overall average of 83.4%. The only other above 90% score was found in Impact Factor 4 (Socialization). The overall average was 83.9%. These were all linked to how the participants reacted to and with other people. The items that scored the lowest were found in Impact Factor 2 (Psychological Effects) and were reversed items: I often fear being rejected by others and I think about my hair loss daily. This Impact Factor also had the most reverse coded items.

Table 42

Impact Factor Frequencies (N = 237)

Factor	M	SD	Frequency				Percent			
			1	2	3	4	1	2	3	4
Impact Factor 1 (Confidence/Self-Esteem) (8)										
I can do things as well as my classmates	3.59	.595	1	10	75	151	.4	4.2	31.6	63.7
I get along well with my family	3.55	.577	0	10	86	141	0	4.2	36.3	59.5
I have many good qualities	3.51	.622	2	10	89	136	.8	4.2	37.6	57.4
I feel that I have the same opportunities as others	3.22	.806	11	23	105	98	4.6	9.7	44.3	41.4
I feel that I am a special person because of AA	2.61	.980	34	76	76	51	14.3	32.1	32.1	21.5
I think about my positive qualities once a day	2.78	.792	13	66	117	41	5.5	27.8	49.4	17.3
I participate in sports with my friends	3.16	.908	16	33	84	104	6.8	13.9	35.4	43.9
My teachers accept me for who I am	3.49	.594	1	9	100	127	.4	3.8	42.2	53.6
Impact Factor 2 (Psychological Effects) (7)										
I often fear being rejected by others (R)	2.57	1.021	52	73	70	42	21.9	30.8	29.5	17.7
I often cry about my hair loss (R)	2.19	.956	28	50	97	62	11.8	21.1	40.9	26.2
I think about my hair loss daily (R)	2.79	.951	64	82	68	23	27.0	34.6	28.7	9.7
People have made fun of me because I am bald	2.67	.996	40	49	97	51	16.9	20.7	40.9	21.5
I prefer to do things by myself (R)	1.98	.888	15	46	96	80	6.3	19.4	40.5	33.8
I avoid being around people (R)	1.79	.827	8	37	89	103	3.4	15.6	37.6	43.5
Having AA makes me angry with myself (R)	2.05	.908	19	46	99	73	8.0	19.4	41.8	30.8

Factor	M	SD	Frequency				Percent			
			1	2	3	4	1	2	3	4
Impact Factor 3 (Appearance/Acceptance) (6)										
I would never change the way I look	2.43	.983	42	94	58	43	17.7	39.7	24.5	18.1
I have accepted my hair loss	2.95	.879	15	52	99	71	6.3	21.9	41.8	30.0
I would like to have a full head of hair	3.49	.768	7	19	61	150	3.0	8.0	25.7	63.3
Having AA does not bother me	2.22	.998	62	95	45	35	26.2	40.1	19.0	14.8
I am okay with the way I look	2.80	.906	22	59	100	56	9.3	24.9	42.2	23.6
I have continued to live my life as it was before	3.10	.853	12	39	99	87	5.1	16.5	41.8	36.7
Impact Factor 4 (Socialization) (4)										
I can make friends easily	3.19	.742	5	32	114	86	2.1	13.5	48.1	36.3
I enjoy hanging out at the mall with friends	3.00	.876	16	43	104	74	6.8	18.1	43.9	31.2
I enjoy going out with my friends	3.60	.627	3	9	68	157	1.3	3.8	28.7	66.2
I have a hard time making friends (R)	1.79	.805	6	39	92	100	2.5	16.5	38.8	42.2
Impact Factor 5 (Communication) (2)										
I have told my friends about my AA	3.24	.767	7	27	106	97	3.0	11.4	44.7	40.9
I am afraid to tell my friends about my AA (R)	2.07	.954	19	59	78	81	8.0	24.9	32.9	34.2

Note. N = 27. 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree

R = Indicates a reverse coded item

Research Question 6: Which Types of Coping Strategies are used Most and Least Frequently by Children and Adolescents with AA?

To answer this question, the data were examined by conducting a descriptive analysis. The strongly disagree and disagree responses were added to indicate one percentage on the disagree end of the Likert-type scale and the strongly agree and agree responses were added together to specify one percentage on the agree end of the scale (see Table 43).

Type of Coping Strategy 1 (Physiological) results revealed that most tried prescription creams (68%), and tried using different types of shampoos and conditioners (53%). However, getting scalp injections (37%), trying different diets (29%), and using doctor prescriptions to feel better (20%) were not the treatments of choice.

Coping Strategy 2 (Cover-up/Avoidance) found that a vast majority of these respondents would tell people about their AA if they were asked (81%). Hats and scarves etc. were used by (47%), hairpieces were not worn all the time (28%) and make-up was not often used (28%).

Type of Coping Strategy 3 (Outside Support) revealed that, although there is community support for children and adolescents with AA, the majority of respondents did not actively use these resources. This was not something these children and adolescents felt they needed or that their parents felt they needed at this time in their life. Only about a quarter of the respondents attended support group meetings (27%), attended a conference (26%), or had individual counseling (22%) in dealing with their AA.

Type of Coping Strategy 4 (Social Network) found that children and adolescents advocated for themselves by looking up information on the internet (76%). However, using social network sites to talk to others about AA (26%) was not often used.

Type of Coping Strategy 5 (Family Support) stood alone as the only item in this group. However, it yielded the highest response in the survey (98%) as a strategy that almost every participant used in dealing with their AA.

Scores over 90% were only found in Type of Coping Strategy 5 (Family Support). The majority of scores were below the 50th percentile with Type of Coping Strategy 3 (Outside Support) having the lowest overall average (25%). Although children and adolescents were struggling with types of treatments to use, concealment strategies, and social networking, the available supports for them were underutilized.

Table 43

Coping Strategy Frequencies (N = 237)

Factor	M	SD	Frequency				Percent			
			1	2	3	4	1	2	3	4
Coping Strategy 1 (Physiological) (5)										
I have used prescription creams	2.78	1.090	48	28	89	72	20.3	11.8	37.6	30.4
I have tried different types of shampoos	2.46	1.091	64	47	79	47	27.0	19.8	33.3	19.8
I have used doctor prescriptions to feel better	1.69	.866	129	61	39	8	54.4	25.7	16.5	3.4
I have tried different types of diets to grow hair	2.05	.986	83	85	43	26	35.0	35.9	18.1	11.0
I have gotten scalp injections for my AA	2.14	1.287	117	33	23	64	49.4	13.9	9.7	27.0
Coping Strategy 2 (Cover-up/Avoidance) (4)										
I wear hairpieces (wigs) all the time	1.99	1.140	112	59	23	43	47.3	24.9	9.7	18.1
I tell people about my AA if they ask	3.12	.767	6	39	113	79	2.5	16.5	47.7	33.3
I wear hats/scarves etc. to disguise my hair loss	2.40	1.102	66	60	62	49	27.8	25.3	26.2	20.7
I use make-up (eyeliner, etc.) to disguise my AA	1.93	1.023	107	64	41	25	45.1	27.0	17.3	10.5
Coping Strategy 3 (Outside Support) (3)										
I have attended support group meetings	1.94	.909	91	83	49	14	38.4	35.0	20.7	5.9
My family and I have attended a conference	2.00	1.105	103	72	21	41	43.5	30.4	8.9	17.3
I have had individual counseling for my AA	1.84	.970	112	72	32	21	47.3	30.4	13.5	8.9
Coping Strategy 4 (Social Network) (2)										
I have looked up information/resources online	3.11	.903	14	43	84	96	5.9	18.1	35.4	40.5
I use social network sites to talk about AA	2.00	.946	83	92	40	22	35.0	38.8	16.9	9.3
Coping Strategy 5 (Family Support) (1)										
My family helps support me	3.71	.516	1	4	58	174	.4	1.7	24.5	73.3

Note. N = 15. 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree

Research Question 7: How do Children and Adolescents Describe the Experience of Having AA Over Time?

The qualitative phase of the study addressed this question. The participants who indicated that they would like to volunteer in a follow-up interview were placed into a table divided by gender, ages, and duration (see Table 44).

Table 44

Follow-up Individual Interview Respondents

Male (2)	Female (2)
Ages 10-13	Ages 10-13
Short Duration of AA (1-6 years) 2 Respondents <ul style="list-style-type: none"> • Brd (11) Long Duration of AA (over 7 years) 18 Respondents <ul style="list-style-type: none"> • Not Available 	Short Duration of AA (1-6 years) 4 Respondents <ul style="list-style-type: none"> • Dey (11) Long Duration of AA (over 7 years) 28 Respondents <ul style="list-style-type: none"> • Mig (11)
Male (2)	Female (2)
Ages 14-16	Ages 14-16
Short Duration of AA (1-6 years) 1 Respondent <ul style="list-style-type: none"> • Des (15) Long Duration of AA (over 7 years) 8 Respondents <ul style="list-style-type: none"> • Mak (15) 	Short Duration of AA (1-6 years) 1 Respondent <ul style="list-style-type: none"> • Lah (14) Long Duration of AA (over 7 years) 22 Respondents <ul style="list-style-type: none"> • Stz (16)
Male (2)	Female (2)
Ages 17-19	Ages 17-19
Short Duration of AA (1-6 years) 2 Respondents <ul style="list-style-type: none"> • Not Available Long Duration of AA (over 7 years) 3 Respondents <ul style="list-style-type: none"> • Mid (17) 	Short Duration of AA (1-6 years) 4 Respondents <ul style="list-style-type: none"> • Emn (17) Long Duration of AA (over 7 years) 21 respondents <ul style="list-style-type: none"> • Nan (18)

The only categories that did not yield any volunteers were the male, ages 10-13 long duration of AA, and male ages 17-19 short duration of AA. Also, since there were no volunteers in the female, ages 14-16, short duration of AA category, the data for the longer duration of AA was examined to find a participant in that category with the shortest duration. That individual was then contacted for the follow-up interview. Ten children/adolescents were interviewed as a follow-up to the quantitative survey. The interview schedule is shown in Table 45. Although the focus group did not take place, one volunteer from that pilot group was willing to participate in an individual interview. She was then interviewed and added to the individual interview data. Since the pilot survey results were added to the overall data, this one individual from the pilot study was added to the individual interview results.

Table 45

Individual Interview Schedule

Date	Partic Pseudo	Interview Location	Time Frame
6-28-13	Nan	Conference Room – St. Louis Hyatt	3 - 3:45 PM
6-29-13	Mig	Conference Room – St. Louis Hyatt	10 - 10:20 AM
6-29-13	Mak	Conference Room – St. Louis Hyatt	4 - 4:45 PM
7-13-13	Brd	Skype – in researcher/their home NE	11 - 11:45 AM
7-15-12	Dey	Skype – in researcher/their home NE	12:00 - 12:35 PM
7-16-13	Lah	Skype – in researcher/their home Mid W	4:45 - 5:15 PM
7-21-13	Emn	Skype – in researcher/their home SW	10:00 - 10:40 AM
8-01-13	Stz	Skype – in researcher/their home NE	2:00 - 2:30 PM
8-22-13	Mid	Skype – in researcher/their home SE	4:00 – 4:30 PM
8-25-13	Des	Skype – in researcher/their home Pacific	3:30 – 4:05 PM
9-15-13	Gaa	Skype – in researcher/their home NE	11:30 – 12:15 PM

Participant interviews varied in length from 20 to 45 minutes and typed responses varied from two to seven pages. Initial categories were generated from the factor analysis and the questions asked in the interviews provided additional data and insight as to how AA affected these children and adolescents in their daily lives.

Throughout the interview field notes were taken and observations were made as to the participant's appearance, voice, gestures, expressions, and emotional state. The researcher conducted all interviews wearing a baseball cap. It was difficult in some instances to see everything that was happening as the Skype window was small. Brd and his mother had to Skype via her phone because they were having computer difficulties. Most participants actively participated in the discussion. Mig, however, was a very quiet and reluctant interviewee and often looked down or to her mother and sister for support. She became tearful when asked what the most difficult situation she had to deal with, with her AA. Gaa also became emotional when thinking back on when she had lost some of her hair. All other participants appeared confident and were able to answer the questions to the best of their ability. Many of the older participants were animated. They all had to learn to adjust to new situations and several were able to laugh at themselves. Participants often hesitated when asked a question they could not immediately answer. They then answered raising their voice at the end as if they were questioning their answer and looking to the researcher for confirmation. The researcher called this a "quesitation." All interviews were recorded and transcribed immediately after the interview. The recordings were again played and additional field notes were added to the original that

were taken during the interview. Several recordings were again played for accuracy and clarification.

Demographics were also collected as part of the interview process (See Table 46). Their ages ranged from 11 to 18 years old. Seven females and four males were represented. All participants were students and six of them stated that they had been bullied because of their hair loss. They represented almost all geographic regions in the United States. Their age of diagnosis ranged from 1 ½ years old to 15 years of age. The number of years these participants have lived with AA ranged from 1 to 15 years.

Table 46

Demographics of Interview Participants

Participant Pseudonym	Age	M/F	Student Yes/No	Bullied Yes/No	Location	Age of Dx	# Years With AA
Brd - S	12	M	Y	N	Northeast	10	2
Dey - S	11	F	Y	Y	Northeast	7	4
* - L		M					
Mig - L	11	F	Y	Y	Pacific	4	7
Des - S	15	M	Y	Y	Pacific	10	5
Lah - S	14	F	Y	N	Midwest	8	6
Mak - L	15	M	Y	N	Rocky Mt.	5	10
Stz - L	16	F	Y	N	Northeast	3	13
* – S		M					
Emn - S	17	F	Y	Y	Southwest	15	2
Mid - L	17	M	Y	Y	Southeast	1 ½	15
Nan - L	18	F	Y	N	Midwest	15	3
Gaa - S	14	F	Y	Y	Northeast	14	1

*Participant not available

Personal Experiences

Personal experiences were shared. Stories were told, some humorous, others embarrassing or with obstacles that were overcome. A few participants had a difficult time recalling a memorable experience in dealing with their AA because they were just living normally with the condition on a daily basis. Many of the participants also shared what they learned from living with AA.

Stories. The data confirmed that, because this condition runs an unpredictable course, the results would be just as varied. All participants reacted differently to their

diagnosis and told different stories. Some had humorous and heartwarming undertones, some spoke about uncomfortable and embarrassing situations, while others were a combination of all these emotions.

For instance, Mak told a story about feeling uncomfortable starting high school without his hat and ultimately decided to just leave it in the car. He stated that, “the first major leap you had to make was to tell people you don’t have any hair.” He went on to say that, “one of the teachers/coaches, who is also bald, came up and put his arm around me and said, ‘God made a few perfect heads and he put hair on the rest. You and me are gonna stick together pal. If anyone messes with you, let them know that they will have to deal with me.’”

Lah shared a story. “There was one time when I was tubing at a lake house and my friend’s dad took a sharp turn and I flew off the tube and when I hit the water my hair came off and I didn’t realize that. I got back out and one of my friends told me and we just saw my hair kind of floating in the lake.” Her facial expressions and tone of voice indicated that she was a bit surprised and mortified in this situation but jumped back in to retrieve her hair.

Mig, who was very quiet and reserved, shared a story about going to Astro camp. The campers had to build things under water. She did not want to participate because she thought that the kids would stare at her, that her presence would interrupt the project, and that wearing a swim cap was not something she wanted to do. She stated, “people stare at me a lot and its annoying.”

Nan skipped a year of cheerleading because she “didn’t want to take on the stress.” Then in her junior year she had a new cheer coach who tried to get her to quit, but she persevered, and by her senior year she was cheer captain.

Stz turned a potentially difficult situation into a project to help others. She started her own non-profit organization called, “Hats for Hope.” She and others at her high school donate new hats for kids who have lost hair to alopecia or cancer at Penn State University. There was also in instance in her life when classmates at school would occasionally ask her “Do you have a hair band?” and she would answer, “No, why did you just ask me that?”

Mid, an older male who has had AA for most of his life told a story about being on his high school football team and tackling an opposing teams quarterback. “I tackled him pretty hard, and he gets up and grumbles that kid can’t even grow a beard.” Mid perceived this as a positive comment.

Lessons learned. All participants realized that although AA is a peculiar condition, it is not life threatening and changed many of them positively. Nan commented that, “I think that it has given me more self-confidence because I always had long hair and I would hide behind it. I can’t do that anymore.” She also shared a “business card” that has her name, a staff of musical notes, and below the staff the words, “My super power is Alopecia Areata, for more info – www.naaf.org” which is the website for the national foundation. Mak was particularly insightful when he stated, “I think it made me much more compassionate toward others with issues.” On reflecting back to when he first began losing his hair, Mak said, “When you lose your hair right

away, it takes a long time to build up resilience. You can be the same person without it.” Stz feels that having AA has boosted her self-perception and stated, “It basically just let me out of my shell. I am more a social butterfly now than I was.” Emn learned, “not to care what other people think and to be yourself no matter what you look like.” Lah was frustrated as a young child having to deal with AA but commented that, “Over time I guess I have accepted it. I knew that I was different from everyone else and I was okay with that.”

Emergent Themes

Sections of the interview transcriptions were placed into categories in an Excel program. These categories indicated areas where the participants added insight regarding their condition. Common threads emerged as did overlapping concepts, which helped the researcher target themes and sub-themes. The following themes emerged from the interview data collected. The participant responses and personal accounts differed based on their age, and extent and duration of their hair loss.

- Coping: Treatments (medicinal, non-medicinal), Support (family/friends, community), and Cover-ups (hits, wigs, etc., comfort and practicality)
- Acceptance: Self Advocate (positive outlook, managing condition)
- Social Issues: Fears/concerns (bullying, stares from others, people finding out), Public Awareness (misperceptions, educate/communicate), and School (bullying, making friends, knowledgeable and caring staff)

A concept map was created using Inspiration 8. It pulls together all the themes to visually clarify and make connections to the information gathered (Maxwell, 2005). It illustrates the three major themes and sub-themes that developed from the interviews and field notes (see Figure 1).

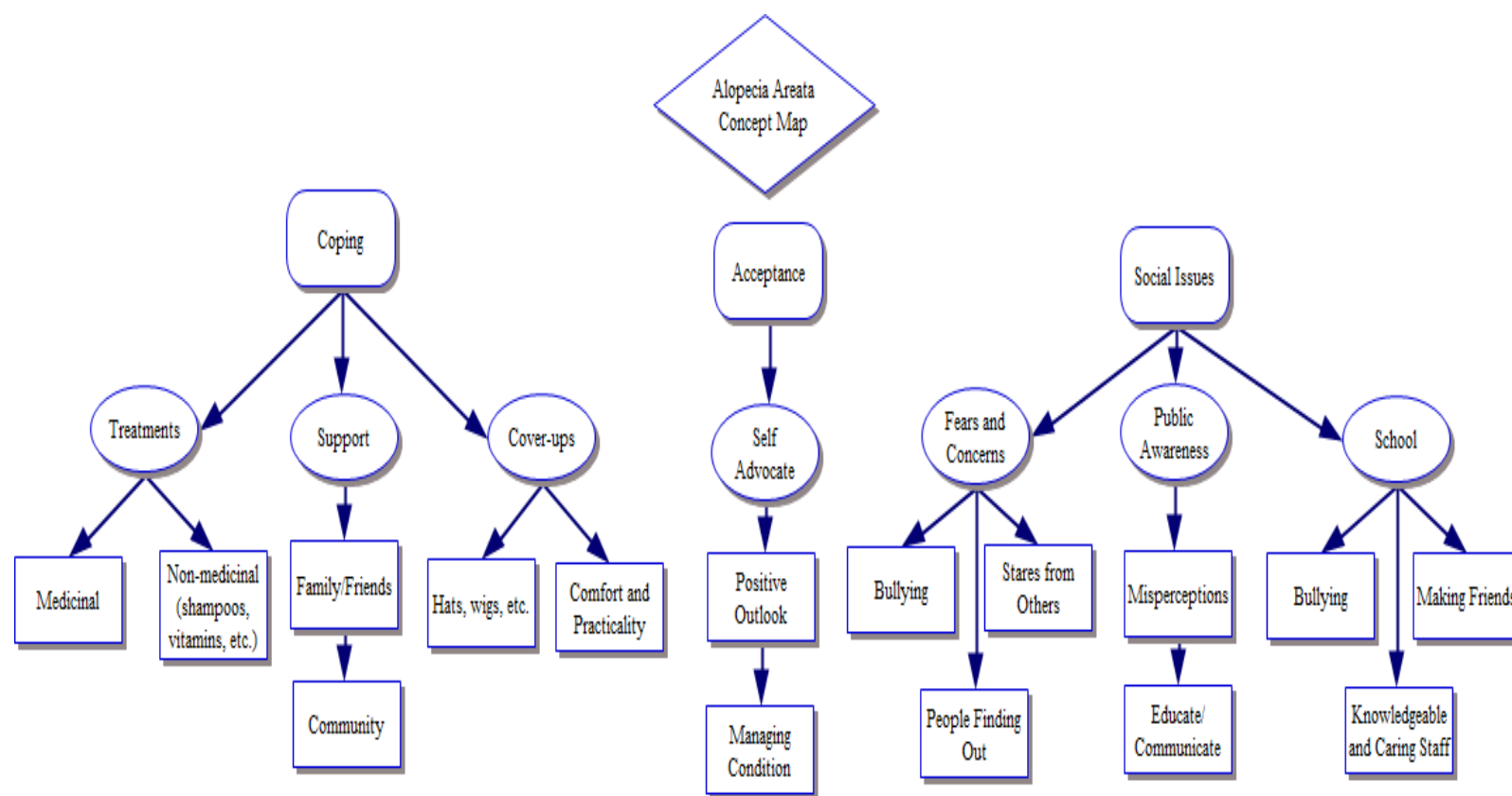


Figure 1. Concept Map of Emergent Themes

Coping. Managing AA can be tricky; it does not run a set course and is quite unpredictable. Some have tried medicinal treatments, but are frustrated with the lack of success. Others have tried shampoos and dietary supplements to no avail. Support from friends and family seemed to be everyone's primary mechanism for dealing with AA.

Most of the participants experimented with some sort of treatment. Medicinal treatments were tried with unsuccessful results. Stz stated, "I have tried biotin shampoos and they don't work, I've tried biotin pills and they don't work either." Another interviewee, Emn, added that, "I tried quite a few shampoos and conditioners just to try and thicken my hair." She also added that "I was just taking a lot of vitamins." Others have adapted by using other approaches. Emn's hair dresser suggested that she take the emphasis away from her hair loss by applying more make-up. Two young ladies were dancers, and in order to blend in, they had to make changes to their looks. Mig commented that she wears, "a headband but it connects with the bandana and on the edges of the headband are little strands of hair." Emn also adapted and stated, "We had to put our hair up and it was really hard to do with my hair because it was so thin; we had to get hair pieces to make it look thicker."

Developing friendships, building relationships, and participating in support groups help individuals with AA better manage their condition (Kalabokes, 2011). Most participants had overwhelming support from their family and friends. Most stated that their friends do not treat them any differently. Participant Dey indicated that, her school guidance counselor helped in that, "every month or so they would check in with me and we would talk about it." Several others stated the importance of friends. Mak was a little

unsure about not wearing his hat when he started high school, but after talking to his friends he recalls, "They were the only reason I was going to be okay with it." In addition, Lah commented, "My friends are great, they support me and they help me." One participant, Stz, commented that, although she did get support from her family, she was a little unsure about how her mother felt, "She takes it upon herself that it's her fault that I have lost my hair." Elkin, Hilker, and Drabman (2006) observed that parents are often concerned about unwanted attention or bullying that could occur due to this condition and want to protect their children at any cost.

Headgear like wigs, hats, and bandanas are used to provide protection, and are common forms of cosmetic cover-up (McKillop, 2010). Of the participants interviewed, only one has grown enough hair back that hats and wigs are no longer needed. The three young men in this study wore hats or just went bald. Several of the young women wore varying alternatives that fit their daily activities. They wore bandanas, headbands, hats, caps, or wigs, depending on the circumstances. Brd wore a baseball cap during the interview and then left half way through to put on and show his Lycra swim cap. Lah had a Cyberhair (a durable, heat resistant fiber that looks and feels like human hair) swim cap that looked like hair that could be used when swimming (What in the Heck is Cyberhair, 2013). Lah was also a gymnast, but abandoned that sport to play volleyball because her wig would, "come up on the back, so I would have to kind of stop and pull it down." A bandana was the head cover-up for Dey. She played soccer and wrote an article called "Bandana Girl" that was published in a local soccer magazine. Her school also had a bandana day. Emn tended to rely on her hairdresser to make decisions that

would conceal her baldness. Mig would usually wear a wig unless she was dancing, then she would modify her look with her headband/bandana. Nan goes bald most of the time, although she does have a wig. She shared that she went to homecoming with just a tiara.

Acceptance. All of the participants advocated for themselves. Some were more vocal than others. Stz commented that, “I like to educate people when they ask me, ‘what is alopecia’ and I would tell them and they are like ‘Oh’, it’s a learning experience for them as it is as much for me.” She also added, “I make jokes about myself, you know, not having hair.” The younger participants did advocate for how they wanted to look, but looked to their parents for support on answering the question.

All participants had a positive outlook even though they were not happy about losing their hair. Dey was positive when she explained, “In the summer when everyone worries about (hair) at the pool and I don’t have to.” Twelve year old Brd commented, “I just feel normal,” having AA “doesn’t feel any different.” Mig, who had good days and bad days stated, “I like not having it too because I do sports and all that stuff and I sweat and it’s not that hot.” Stz viewed having AA as a positive experience when she said, “It really doesn’t bother me. I think it’s great and it has given me a different, like a whole different perspective on how other people view it.” Gaa was familiar with AA because her mother had an AA episode in her life. She recalls, “I was not surprised. My mom had a little bit, but not as severe. I was just going to let it run its course.”

When managing their AA, all participants had a particular preference. Dey wore bandanas, Emn and Lah used hairpieces, while Mig uses an assortment of hairpieces for various activities, Nan would wear wigs from time to time, Stz would either go bald or

wear hats, and the males in the group either went bald or wore caps. All participants had tried some type of medicinal treatment. Emn used numerous treatments and was happy when her dermatologist told her that she would not have to come back again because her hair was growing.

Social issues. The number one fear or concern that these young people had was losing their hairpiece, hat, or bandana in public, which could possibly cause an embarrassing situation. This seemed to cause the females more anxiety than males. Research shows that males are more confident in dealing with their hair loss than females and bald males are seen as more acceptable in society (Hunt & McHale, 2005a). Therefore, more coping measures are required for females. Lah was uneasy about going out in public because people, “do stare because I don’t have eyebrows or eyelashes, and I kind of just look away.” Emn found it difficult to do gymnastics due to wig malfunctions. She was also concerned that she might not make lots of new friends, “I could have been making a lot of new friends if my hair was longer, if my hair was thicker, but I guess that’s not really the truth, I just felt that way.” Mig and Lah seemed especially sensitive when others stared at them, probably trying to figure out what made these individuals different. Mig also did not want to disrupt a camp activity at a pool, so she did not participate. When it came to strangers, Nan commented that, “Once someone ignored me because of it. It hurt me at first, but then I don’t know why I was upset about it, but it’s their problem.” Dey was concerned about her hair loss, especially on picture day, “where everybody is adjusting their hair.” Nan took off a year of cheerleading

because she did not know how stressful losing her hair would be, “I didn’t know yet how I was going to cope with it.”

AA is an obvious visible condition and is, therefore, difficult for others not to notice that something is different (Welsh & Guy, 2009). Some of the participants were able to ignore the stares, or insensitive comments of people outside their group of family and friends. Others had misconceptions of how people would react to their hairless look. Nan was confronted at a community pool by a young girl who stated that she “looked like a boy.” She did not take the comment personally and just told the child she was a girl. Emn was confronted by, “this one particular girl” at school who asked, “Why is your hair falling out?” She simply replied, “It is not any of your business.” An increase in public awareness may make these children and adolescents more of a commonplace occurrence than an oddity.

When asked about school experiences, most participants responded positively, mostly due to friendships and activities in which they were involved. Brd and Mak were permitted to wear their hats in school. Dey reflected back to when she was first diagnosed and was completely bald and stated, “One point in time it was hard going to school,” but added that, “I had a plan with my school where I could wear headbands and hats.” She also requested a short video from the NAAF that explains what AA is all about and was able to share it with her school. In contrast, Stz used humor when dealing with her AA. She would wear hats in school and explained that, “My friends would usually rip them off my head and run down the hallway with them.” According to Stz this was all done in good-humor and the way she describes it, helped her cope. She enjoyed educating people

about this condition and added that “It’s a learning experience for them as it is as much for me.” Mid appeared indifferent. He had AA most of his life as he was diagnosed at 1½ years of age. “I played outdoor soccer, little league, and soccer, and in high school I played baseball, basketball, and football.”

Additional Connections

A word cloud was created from the text of the interview transcripts. A word cloud visually illustrates words that are used most frequently used and viewed as the prominent words of the text (Tagxedo, 2013). This word cloud indicates that the children and adolescents interviewed were most concerned with *hair, people, friends, and school* based on the largest font words (See Figure 2). While these children and adolescents were living their lives and learning to adapt to their new identity they all had difficulty adjusting to a certain degree. Many had to explain their look to strangers, some were the target of jokes, harmless or not. The words, *bothered, hard, questions, hiding, and stare* were also prevalent while explaining how this condition impacted their lives. Due to the fact that they all had strong support systems, this group of children and adolescents were proactive and had a positive outlook. They were able to identify lessons learned, most participants promoted awareness, they inspired others, recognized the individuals who encouraged and supported them, and continued to persevere through the daily trials of adolescence.

The word cloud words are also linked to the three themes. Coping is linked with treatments (*injections, dermatologist*), support (*friends*), types of cover-ups (*bandana, caps*). Acceptance is seen in (*myself, try, ask, adjusting*). Social issues linked to fears

factors, as well as gender and duration of AA. Age and onset of AA were also compared to the types of coping strategies, as well as gender and duration of AA. Impact factor and type of coping strategy frequencies were calculated with *I get along well with my family* and *my teachers accept me for who I am* as being the most frequently cited items under impact factors (96%) and *My family helps support me* as being the most frequently cited item under type of coping strategy (98%). Three main qualitative themes developed out of 11 follow-up interview participants: Coping, Acceptance, and Social Issues.

5. DISCUSSION

In this chapter the researcher examines participant demographics and the meaning of the results on each of the seven research questions. Conclusions and implications are discussed as to their effect on children and adolescents. The discussion examines the results related to the following impact factor questions.

Research question 1: What are the factors that impact children and adolescent with AA?

Research question 3: How do the impact factors differ by group (e.g., age, gender, onset, duration)?

Research question 5: Which individual impact items have the greatest and least influence on children and adolescents with AA?

The discussion also examines the results of the following types of coping strategies questions.

Research question 2: What types of coping strategies are used by children and adolescents with AA?

Research question 4: How do the types of coping strategies used differ by group (e.g., age, gender, onset, duration)?

Research question 6: Which types of coping strategies are used most and least frequently by children and adolescents with AA?

Group comparison findings indicated that Impact Factor 1 (Confidence/Self-esteem) presented with the highest scores and Type of Coping Strategy 5 (Family Support) was cited most frequently. This may suggest that a child and adolescent's self-esteem may be linked to the support they are receiving at home. Impact Factor 2 (Psychological Effects) items were generally cited least frequently and Type of Coping Strategy 3 (Outside Support) presented with the lowest scores. This suggests that the use of outside supports may impact the psychological effects on children and adolescents.

This chapter will also explore research question 7: How do children and adolescents describe the experience of having AA over time? This question examines the qualitative themes of acceptance, social issues, and coping and how they are linked to the impact factors and types of coping strategies. The interviewees indicate that family and friends were the most important coping strategies used. Most also did not view treatments and cover-up as an essential part of their lifestyle. Qualitative insights are used to connect the survey results with the insights of individual interviews. Finally, limitations to the study, practitioner application, and recommendations for future research are addressed.

Observations about Participant Demographics

This research confirmed that of the 237 respondents to the survey, female respondents outnumbered males two to one. Not only were more females represented in the survey, but more female respondents were available across all interview categories. Consequently, two of the interview categories for males were incomplete; one in the

10-13 long duration and one in the 17-19 short duration categories. This difference in responsiveness by gender was echoed by Kyser (1993) and Pennington (1993) showing that female participants more than doubled the number of male participants. In addition the female participants had difficulties in dealing with their physical change, which resulted in seeking out support and using cover-up alternatives more often than their male counterparts. Welsh and Guy (2009) agree that women had a more difficult time adjusting to their hair loss. Males were more successful in managing their hair loss because bald men are viewed as appearing more acceptable in society (Hunt & McHale, 2005a).

Neither gender was spared from being bullied. Of the participants in this study 46% indicated that they had been bullied at some point in their life. Of the 11 individual interview participants, 55% stated that they had been bullied. Harrison and Sinclair (2003) concur that children with AA are likely to be ridiculed at school and can lead to stress, anxiety, and depression. Dawkins (1996) explains that when children are asked why they are bullied, they refer to their physical attributes.

Conclusions and Implications Regarding Impact Factors

Five impact factors were identified through the factor analysis. All five impact factors link clearly with literature review findings and qualitative themes. The impact factors identified were: (1) Confidence/self-esteem, (2) Psychological effects, (3) Appearance/acceptance, (4) Socialization, and (5) Communication. A comparison between the literature and impact factors can be seen in Table 47.

Table 47

Comparisons between Literature and Impact Factors

Literature Review-Based Impact Factors	Impact Factor
Psychological Effects Stress Depression/sadness Anxiety School issues Insecurities/inadequacies Withdrawal Embarrassment Discouragement Guilt	Impact Factor 2 (Psychological Effects)
Advocacy/Acceptance Confidence Independence Self-worth Vulnerability Ability to cope Use of humor	Impact Factor 1 (Confidence/Self-Esteem) Impact Factor 3 (Appearance/Acceptance)
Personal Appearance Distress/concern Self-image (positive vs negative) Discrimination Peer abuse/bullying Behavior problems Socialization Isolationist	Impact Factor 3 (Appearance/Acceptance) Impact Factor 4 (Socialization)
Support Family Friends Groups	Impact Factor 5 (Communication)

Impact factor 1 (confidence/self-esteem). While AA can affect a young person's appearance and cause psychological strains, the survey respondents revealed a positive attitude about themselves. The majority indicated that they were as capable as

their peers, had admirable qualities, participated in sports with friends, and were accepted by family, friends, and teachers.

The factor analysis revealed this area of eight items as having the strongest influence on children and adolescents. The loading scale ranged from a .518 to a .661. Of these items the two most frequently cited by respondents were, *I get along well with my family* (96% agree/strongly agree) and *My teachers accept me for who I am* (96% agree/strongly agree). The item least supported by the respondents was, *I feel that I am a special person because of AA* (54% agree/strongly agree). When comparing gender and duration with this factor, the results were not significantly different.

However, a significant difference was found in the age groups. The younger aged (10-13) group had higher rates of confidence and self-esteem than the two older groups. Onset of AA also resulted in a significant difference. The earlier onset group had more confidence than those acquiring AA at an older age. Adapting to a new identity takes time and can be influenced by family, peers, and the media (Anderson & Skemp, 2012). These authors also commented that a person's body image is connected to their self-confidence.

Impact factor 2 (psychological effects). Having a physical anomaly could be difficult to handle. The majority of children and adolescents in this study were affected in some way by this condition. Previous research has focused on adults as well as on the psychological issues of children and adolescents.

The factor analysis loadings of the seven items in this component ranged from .572 to .743. The item respondents most frequently cited was *I avoid being around*

people (81% agree/strongly agree). The least supported item in this group was *I think about my hair loss daily* (38% agree/strongly agree). Beard (1986) suggests that individuals with AA can be made to feel inadequate and may be seen as outcasts. Children and adolescents with disabilities are at risk of being excluded from activities (Asbjornslett et al., 2011).

However, 53% of the participants in this study were not concerned about being rejected by others. This may be due to the fact that most individuals had overwhelming support from family and friends. When comparing gender on Impact Factor 2, there was a significant difference indicating that dealing with AA is more challenging for females than males. Women find daily activities problematic. Many do not want to be seen in public and others have tried to avoid work (Hunt & McHale, 2005a; Van Der Donk et al., 1994). Hunt and McHale (2005a) also found that some of their participants experienced psychological distress they “felt like a freak” and “were ashamed to go out.” No significant difference was seen for duration in Impact Factor 2. Age compared to Impact Factor 2 resulted in a significant difference.

Having to deal with the psychological effects of AA was more difficult with an onset later in life. The older participants had a more difficult time adjusting than the younger group. This could be due to the fact that older teens want to fit in with the norm of physical appearance and body image (American Psychological Association, 2002). The results for onset and this factor yielded a significant difference. This may be linked with establishing a sense of identity (Anderson & Skemp, 2012).

Liakopoulou et al. (1997) found that the children in their research suffered from anxiety, depression, and withdrawal due to their AA. Many were also embarrassed and saddened by their hair loss. Hunt and McHale (2005b) also remarked that children with AA showed more signs of anxiety, depression, and isolationist behaviors. The survey results supported these statements in items, *I prefer to do things by myself* (74%), *I avoid being around people* (81%), and *I often cry about my hair loss* (67%).

Impact factor 3 (appearance/acceptance). Research reports that the loss of hair may impede the ability to cope (Anderson & Skemp, 2012). The majority of participants reported that having AA was troublesome. Although most wished to have a full head of hair, many learned to accept their hair loss.

The factor analysis loading for these six items ranged from .412 to .759. The most frequently cited item by the respondents was *I would like a full head of hair* (89% agree/strongly agree). The least supported item was *I would never change the way I look* (43% agree/strongly agree). There was not a significant difference between gender or duration on Impact Factor 3. However, there was a significant difference between age and onset. The younger group was more accepting of their hair loss than the older group. Participants who developed AA earlier were more accepting of their appearance than those who acquired it later in life. These results suggest that having hair, being perceived as normal, and fitting in socially are important to these older participants. One of Hunt and McHale's (2005a) participants felt they had a pig-like appearance due to their lack of eyelashes and eyebrows which give the face definition.

People are more accepting of diversity today than they have been in recent decades. People are more tolerant on social issues (The Pew Research Center, 2007). Accepting an altered appearance is difficult and individuals often question their identity (Koszalindki & Williams, 2012). They experience feelings of insecurity due to lack of confidence.

The results of this study conflict on this issue. One item, *Having AA does not bother me* (66% disagree/strongly disagree) and on the other hand, item *I am okay with the way I look* (66% agree/strongly agree). This discrepancy could be due to the fact that although most participants find having AA is bothersome, they have adapted to their new appearance. Welsh and Guy (2009) report that coping strategies improve over time and that age and other priorities help in managing their condition. The support of friends and family could also be a source of this acceptance. Buri (1989) stated that there is a connection between parental support and acceptance and a child's self-esteem.

Impact factor 4 (socialization). The majority of participants felt that they made friends easily and enjoyed hanging out with their friends. The results also indicated that the majority also had a hard time making friends. It is difficult to say why this discrepancy occurred. This question was reverse coded. Perhaps the question was not interpreted correctly or maybe there was a time in the individual's life when initiating a friendship did not go well. Making friends in a familiar surrounding like school or home may be easier than in an unfamiliar one. It could also be that people view themselves as friendly, but do not like initiating friendships. Hunt and McHale (2005a) found that

young people had difficulty coping in school and handling reactions from those unfamiliar with AA.

The factor analysis loading on these four items ranged from $-.664$ to $.765$. The most frequently cited item was *I enjoy going out with my friends* (95% agree/strongly agree). The least cited item was *I enjoy hanging out at the mall with friends* (75% agree/strongly agree). When comparing gender to Impact Factor 4, the results showed a significant difference. Females tended to socialize more easily than males. Perhaps this has to do with the fact that bald males are more acceptable in society and do not have to try as hard to socialize to fit into the norm. Silverberg (2006) expressed that a child's well-being is influenced by his/her self-esteem and ability to socialize. Connecting with others can alleviate the feeling of being alone and maintain some degree of normalcy (Prickitt et al., 2004). Duration and Impact Factor 4 did not produce any significant difference as to duration of having AA and socializing. There also was no significant difference between a person's age and onset with socializing.

Impact factor 5 (communication). Most of participants were able to effectively communicate their condition to others. However, the majority were afraid to tell friends about their condition. Telling others about AA could be worrisome and cause some apprehension. However, revealing loss of hair to friends could also bring about peace of mind. It could be that it was easier to tell current friends about their condition, whereas, it might be more difficult to explain their condition to newly introduced acquaintances.

The factor analysis included only two components. The item, *I am afraid to tell my friends about my AA* loaded at $-.611$ and *I have told my friends about my AA* loaded at

.703. Of these two items, *I have told my friends about my AA*, was more frequently cited by the respondents (86% agree/strongly agree). While *I am afraid to tell my friends about my AA* was cited (67% agree/strongly agree) and was reverse coded. Children interviewed through NAAF suggested that classmates should be told about AA so that they would have an understanding as to what AA is (NAAF, 2011b). An addition, communicating with family and friends is a way to deal with depression (Sawyer et al., 2012). A significant difference resulted when comparing gender to communication scores, indicating that females were more willing to tell their friends about their condition. Duration did not yield a significant difference. Age and onset also did not result in a significant difference.

Conclusions and Implications Regarding Types of Coping Strategies

Five types of coping strategies were identified through the factor analysis. All five types of strategies linked with literature review findings. The types of coping strategies identified were: (1) Physiological (medicinal and alternative treatments), (2) Cover-up/Avoidance, (3) Outside Supports, (4) Social Network, and (5) Family Support.

Matzer et al. (2011) found that individuals with good coping skills were less negative and had a more positive body image. A comparison between the literature and types of coping strategies can be seen in Table 48.

Table 48

Comparisons between Literature and Types of Coping Strategies

Literature Review-Based Coping Strategies	Type of Coping Strategy
Medicinal Treatments Consultation with various doctors Over-the-counter Prescriptions (anti-depressants) Injections Prescriptions (creams, lotions etc.)	Type of Coping Strategy 1 (Physiological - medicinal and alternative treatments)
Alternative Treatments Massage PUVA Hypnosis Relaxation training Shampoos/conditioners Diets/vitamins Acupuncture Surgery (hair plugs)	Type of Coping Strategy 1 (Physiological - medicinal and alternative treatments)
Cosmetic Cover-up Hats/scarves/hairpieces Make-up Permanent make-up	Type of Coping Strategy 2 (Cover-up/Avoidance)
Community/Outside Support Support groups School support Individual counseling Professional organizations Research participants Medical experts	Type of Coping Strategy 3 (Outside Support)
Communication/Technology Online support from friends Educating and telling others online Personal written accounts Use of social network sites Research online Chat rooms	Type of Coping Strategy 4 (Social Network)
Family Support Educating others/awareness Encouragement Protection Connecting with other families	Type of Coping Strategy 5 (Family Support)

Type of coping strategy 1 (physiological). This type of coping strategy includes medicinal and alternative treatments. Most participants tried different types of shampoos and conditions, as well as prescription creams. Other treatments were not readily used by this group of participants. This could be due to the age of these participants, as well as the negative side effects of some treatments.

The factor analysis suggests this area as having the strongest influence on children and adolescents with AA. The five items from the scale loaded with a range from .395 to .775. The most frequently cited item was *I have used prescription creams* (68% agree/strongly agree). The least cited item was *I have used doctor prescriptions to feel better* (20% agree/strongly agree). No significant difference in responses regarding physiological strategies was found when comparing genders. There was a significant difference relative to duration. Participants experiencing a shorter duration tended to try a variety of treatments. This could have to do with being newly diagnosed and looking for a cure. When comparing age groups, this type of coping strategy revealed a significant difference. The older participants tended to experiment and use more treatments than the younger participants. This may be due to the fact that the parent would have a greater say in the treatment regimen for a younger child. Age of onset also produced a significant difference. Participants who were diagnosed when they were older tended to try more treatments.

Treatments are usually started when a person is initially diagnosed and a variety of treatments could be tried over a long period of time. Also the earlier a child is diagnosed, the prospects for reversal is more likely (Liakopoulou et al., 1997).

Treatments were tried slightly more with the older group of participants in this study. This perhaps had to do with the connection with one's body image and wanting to be accepted by peers (Egan & Perry, 1998). Being under age, younger participants would need guidance and approval from their parents in order to try treatments. In addition, some treatments can be painful and irritating (Nield et al., 2006) while others can cause fluctuation in pulse rates and low blood pressure; therefore, caution should be used when administering to vulnerable populations (Georgala, Befon, Maniatopoulou, & Georgala, 2007). Random treatments should not be offered because they only offer a false sense of hope and could increase anxiety (MacDonald, 1999).

Type of coping strategy 2 (cover-up/avoidance). The use of make-up was not used frequently by children and adolescents. This was probably due to their age and active lifestyle. In addition, make-up is traditionally worn by females, but both males and females participated in this study. The results of this study did not support use of make-up as a coping strategy, *I use make-up (eyeliner, etc.) to disguise my AA* (28% agree/strongly agree). Strategies to conceal the loss of hair were also not frequently used by children and adolescents. The participants responded, *I wear hairpieces (wigs) all the time* (28% agree/strongly agree) and *I wear hats/scarves etc. to disguise my hair loss* (47% agree/strongly agree). This could be linked to the fact that these children and adolescents were leading active lives, had accepted their hair loss, and were okay with their appearance.

The factor analysis resulted in four items loading from .358 to .669. The most frequently cited cover-up/avoidance strategy was *I tell people about my AA if they ask*

(81% agree/strongly disagree). The least frequently cited item was *I wear hairpieces (wigs) all the time* (28% agree/strongly disagree). A significant difference resulted when comparing gender with this type of coping strategy. Cover-up/avoidance was a strategy used more by females. Comparing responses by duration did not result in a significant difference. A significant difference was found when comparing age groups indicating that older participants tended to use more cover-up strategies to conceal their hair loss. Age of onset also produced a significant difference. Participants who developed AA later in life tended to use cover-up more readily than those who developed it early on in life. Females tend to seek out support, use make-up, and wear hairpieces more often than men (Van Der Donk et al., 1994). McKillop (2010) verified that cover-up for women can take on many forms including: hats, scarves, hairpieces, hair extensions, and permanent make-up. Welsh and Guy (2009) concur that women have a more difficult time adjusting to their hair loss.

Type of coping strategy 3 (outside support). Professional conferences and support group meetings were not readily used by the participants in this study. Research, however, reveals that support groups and counseling give people a sense of belonging when they think they are alone with this condition (Hunt & McHale, 2005b). These conflicting results may have to do with the age of the children and adolescents who are unable to attend meetings or conferences unsupervised. It may also be that attending a support group or conference makes the condition inevitable. Welsh and Guy (2009) noted that one of their study participants felt that the support group experience was depressing

and negative. It also could be that information and the ability to connect with others online is more readily available.

The factor analysis found three items that loaded with a range of .462 to .813. The most frequently cited item was *I have attended support group meetings* (27% agree/strongly agree), the second most frequently cited item was *My family and I have attended a conference* (26% agree/strongly agree), and the least frequently cited item, *I have had individual counseling for my AA* (22% agree/strongly agree). None of the three items were cited substantially more than the other. Comparison of gender and duration relative to this type of coping strategy did not reveal significant differences. Comparison of age groups did result in a significant difference. The younger participants used more outside support to help them manage their AA. The reason could be that the parent initiated the contact and also needed support in helping their child. When comparing age of onset and outside support, no significant difference was found.

Individuals who attend support groups gain a greater ability to cope than those who do not attend (Pennington, 1993). While these results reflect Pennington's research that was based mainly on adults, this is still sound practice for individuals experiencing situations that are unfamiliar or troublesome. The lack of attendance at support group meetings, conferences, or counseling by participants in this study could also be that the meeting times and places were inconvenient, the cost of attending was not financially possible, or perhaps these meetings were not effectively advertised to reach all individuals affected by AA.

Type of coping strategy 4 (social network). Connecting online to social network sites was used more by the older aged participants. Parental control may be a factor in limiting access with the younger participants. Parents should be proactive and discuss what sites are acceptable with their children and set guidelines.

The factor analysis identified two items. They loaded from .740 to .765. The most frequently cited item was *I have looked up information/resources online* (76% agree/strongly agree). The second item, *I use social network sites to talk about AA* (26% agree/strongly agree). The comparison of gender relative to use of social network produced a significant difference. Females tended to use social networking more often than males. Duration category comparisons did not reveal a significant difference. When comparing age groups, there was a significant difference between the mid group and the youngest group. The mid group tended to use social networking more often. Age of onset comparisons also revealed a significant difference. Onset of AA later in life leads to the use of social networking to find information and resources and to connect with others with AA.

Maintaining existing friendships was one of the main reasons young people communicate using the internet (Subrahmanyam et al., 2008). In this study the vast majority (76%) did use online resources to look up information. Research indicates that there are numerous resources for individuals online. The NAAF provides its members with online services such as their electronic newsletter, website, Facebook, and Twitter sites (NAAF, 2011d). Sawyer et al. (2012) noted that when seeking help, females would rather contact friends, school counselors, and telephone help lines while males would

consult with their physician or the internet. However, Kyser (1993) found that females tended to use online supports, especially for the purpose of researching information on AA. This study confirms the fact that females reported greater socialization effects and a greater impact on communication than did their male counterparts.

Type of coping strategy 5 (family support). Family support was the most frequently cited type of coping strategy noted by children and adolescents with AA in this study. This corroborated previous findings that the support of family and friends can improve an individual's self-esteem and encourage positive social interactions (Rumsey & Harcourt, 2004).

The factor analysis identified only one item loading at $-.752$, in the family support area. The possible reasoning is that there were no other questions dealing with family support. This item scored higher than any other item in the analysis *My family helps support me* (98% agree/strongly agree). Comparing gender and duration revealed no significant difference. While the comparison of age relative to family support did not result in a significant difference, Tukey's HSD did not produce significant differences between the age groups indicating they were all equally influenced by the support of the family. The comparison of age of onset groups resulted in a significant difference. The participants who experienced hair loss earlier relied more heavily on family support than those diagnosed later in life. This could possibly have to do with the maturity level of the individual.

The family support category in the literature review confirmed that support from family and friends gave individuals with AA feelings of acceptance and that support

networks can improve and individual's self-esteem (Welsh and Guy, 2009). Rumsey and Harcourt (2004) add that during personal struggles, family support can alleviate fears and reduce stress. This study confirms the importance of family support.

Qualitative Insights

The 11 interviewees were able to clarify and explain gaps in the survey data. Of the 11 participants, three had AA for an extended period of time: Mak, Stz, and Mid (refer back to Table 46). These individuals appeared confident, had a positive outlook, and, at times, seemed indifferent to their diagnosis of AA. They were continuing with their lives and refused to change activities and lifestyle due to AA. On the other hand, another three had AA for a very short period of time: Brd, Emn, and Gaa. Of these participants, Emn and Gaa, both females had grown their hair back. Brd, being a young male also seemed indifferent to his diagnosis at this point in his life. He had the support of family and friends, and participated in several sports. The main qualitative themes (see Table 30) are addressed and linked with the Impact Factors and Types of Coping Strategies that were covered in the beginning of this chapter.

Table 49

Qualitative Themes

Acceptance						
Self-Advocate Positive Outlook Managing Condition						
Social Issues						
Fears and Concerns			Public Awareness	School		
Bullying	Unwelcome Stares	People finding out	Misperceptions Educate Communicate	Bullying	Making friends	Educated and caring staff
Coping						
Treatments		Support		Cover-ups		
Medicinal	Non-medicinal (shampoos, vitamins, etc.)	Family/Friends Community		Hats, wigs, scarves etc.	Comfort and Practicality	

Acceptance with links to impact factors. Although research reported that the loss of hair may impede the ability to cope, which could then lead to self-esteem issues (Kyser, 1993), most of the children and adolescents in this study did not perceive themselves as being abnormal. They had support from their family and friends, which was confirmed by the survey data, and were able to live a healthy active lifestyle. This was supported by the respondent's comments. Mid, a 17 year old felt that having AA was "Something that made me feel unique." Brd, who was seven years younger stated, "I just feel the same, I just feel normal." Stz thought that her self-image "was actually better than it was." Dey reported, "After a while you do get used to the way you look." Lah

shared, “I knew I was different from everyone else, and I was okay with that.” Nan agreed, “It has given me more self-confidence.” However, Des commented, “I just wanted to blend in and be normal. . . For me it has been really hard for my self-confidence and to be confident with who I am and how I look with AA.”

Of the 11 interviewees, six chose to go bald or wore baseball caps. This group included all four males and two of the female participants. The remaining five participants were females. Two had grown most of their hair back and the other three wore hair pieces on a daily basis. Several basically established a new identity. Dey would wear bandanas and was known as “bandana girl.” She commented, “I used to wear a bandana and now I still kind of wear it as a decoration.” Mak stated that “The first major leap you had to make was to tell people you don’t have any hair, which for me was the first day of school. I left my hat in the car.” The participants who were bald for their interviews presented as being outgoing and self-confident. Several also stated that going bald no longer bothered them.

These comments were linked to the survey results in that the younger participants and those with an earlier onset of AA were more accepting of their hair loss. Respondents to the survey verified these comments (66% agree/strongly agree) to Impact Factor 3, item *I am okay with the way I look*.

Most of the interviewees were resigned to the fact that AA was now a part of their life. Dey verifies, “I sort of see myself as the same person now.” Nan spoke about hoping her hair would grow back and added, “If I had real hair, I wouldn’t know what to do with it anymore.” Lah was a little hesitant but said, “I was upset about it when I was

younger, but now, I think I have learned to live with it.” These comments link to Impact Factor 3 item, *I have accepted my hair loss* (72% agree/strongly agree).

Social issues with links to impact factors. Two of the female interviewees became tearful while being interviewed. Gaa became emotional when she was asked about how other people made her feel. She replied, “I stuck with my friends and they were like, fine.” She also added, “Everybody thinks it’s not a big deal, it’s just your hair. You really don’t understand until you are the one who is going through it.” Mig, became emotional after being asked about her self-perception and answered, “I always look at magazines and see the long beautiful hair.” Liakopoulou et al. (1997) found that girls had more difficulty adjusting to their new self-image and had problems with their self-esteem which led to depression. Results from the survey relative to Impact Factor 2 (Psychological Effects), indicates that older females had more difficulty psychologically in adjusting to their hair loss than males.

All of the participants were involved in outside activities such as: (a) band, (b) dance, (c) volleyball, (d) soccer, (e) theatre, (f) football, (g) baseball, (h) basketball, (i) track, (j) cheerleading, and (k) swim team, so staying isolated from others was not an issue. Respondents replied, *I participant in sports with my friends* with (79% agree/strongly agree). Due to their participation in extracurricular activities, all interviewees had a group of friends with a common interest.

Some of the participants preferred to do things alone and avoided being around people. Nan took a year off from cheerleading because she “didn’t want to take on the stress.” However, a year later she was back on the squad. Mig avoided an underwater

camp activity because she thought she would be, “distracting to other kids,” but she dances on a regular basis. Des commented, “A lot of the time I just wanted to stay at home.” These comments connect to Impact Factor 2 (Psychological Effects) item *I prefer to do things by myself* (74% agree/strongly agree) and *I avoid being around people* (81% agree/strongly agree). It is difficult to hide the fact that you are losing hair, therefore, some people choose to avoid others (McKillop, 2010).

Most interviewees noted that they were frustrated, annoyed, and fearful of other’s comments and unwanted attention. Des comments, “People a lot of times would just stare at you and you can tell that they are judging you.” Lah adds, “It’s hard to meet and go in public sometimes because some people do stare.” Mak agrees, “People are going to stare and see me as abnormal.” Mig, crying, stated, “People stare at me a lot and it’s annoying.” Impact Factor 2 (Psychological Effects) clarifies, *I often cry about my hair loss* (67% agree/strongly agree). Hunt and McHale (2005a) reported that the fear associated with AA had to do with the individual’s altered appearance. Des, who was self-conscious about his appearance, described a situation where he was bullied in school by an older student, “He would say these snarky comments when no one was around . . . I played sports with him and he would hit the ball at my legs.” When a child or adolescent is perceived as lacking confidence they could be victimized by peers (Egan & Perry, 1998). These comments are verified by Impact Factor 2 (Psychological Effects), *People have made fun of me because I am bald* (62% agree/strongly agree).

Most participants just wanted to look like everyone else. Hair loss can be especially difficult for teens as they just want to blend in with their peers without feeling

loss or grief (Smith, 2001). The evidence from this study confirms that children and adolescents also wanted to blend in with their peers. Emn stated that she felt “uncomfortable at school and people were asking me why I cut my hair short.” Mig the youngest female participant had the most difficulty, “I just want to be like other people.” Des added, “I just wanted to blend in and be normal.” This study supports these comments *I would like to have a full head of hair* (89% agree/strongly agree).

Many people also equate being bald to having cancer. Des dealt with this misperception, “People thought I had cancer and they were always like kind of trying to make sure I was okay.” Both Gaa and Stz commented that people would ask them, “Do you have cancer?” They would then have to explain what AA was. This brought about awareness which is what individuals with this condition need. By educating others, this misconception could be erased (McKillop, 2010). Impact Factor 5 links with item, *I have told my friends about my AA* (86% agree/strongly agree).

All of the interviewees had told a friend about their condition. While this was difficult for some, it opened up communication. Mid commented that, “A lot of people ignore us, because I think maybe they are afraid to ask. They are afraid to find out that this is not something that is going to kill us.” Dey adds, “I have friends that I can talk to about it when sometimes it gets rough.” Individuals were empowered to either share information about their condition or hold back information (Matzer et al, 2011). Mid, being an older, larger male eventually had to tell the people he was hanging out with because, “people just assumed that I shaved my head.” Mak felt that “The first major leap you had to make was to tell people you don’t have any hair.” Emn confessed, “It

was really hard at first, because I didn't feel comfortable at school and people were asking me why I cut my hair short. "I didn't really tell many people about it, I only told my really close friends." Stz started her own non-profit organization with friends at her school who collect hats to donate to students who have AA or cancer at Penn State.

Good friends contribute to psychological well-being (Asbjornslett, Engelsrud, & Helseth, 2011). Mak commented, "I don't feel any different when I am around my friends." He also felt that AA had made him "more compassionate toward others with issues."

Impact Factor 4 (Socialization) clarifies these statements, *I can make friends easily* (84% agree/strongly agree), *I enjoy going out with my friends* (95% agree/strongly agree), and *I enjoy hanging out at the mall with friends* (75% agree/strongly agree). Results from the survey relative to Impact Factor 4 (Socialization), indicate that, females reported socializing more than their male counterparts.

One participant found it difficult to make and maintain friendships. Gaa stated, "I have a new group of friends that aren't the same as the ones in 8th grade." "My friends are more supportive now." Gaa's statements link to Impact Factor 5 (Communication). The respondents to the survey verified item *I have told my friends about my AA* (86% agree/strongly agree) but then contradicted item *I am afraid to tell my friends about my AA* (67% agree/strongly agree). The reasoning could be that the types of friends and their maturity level changes throughout schooling and therefore, makes it difficult to determine with whom you should share a confidence.

Types of coping strategies linked with factors. Many of the younger interview participants were unable to recall if they had any medical treatments. Only a few of the

interviewees tried scalp injections without success. Des shared, “I did get injections in my eyebrows.” Stz commented, “I got steroid shots in my head, but that was not doing anything, so I was like, I’m just going to let it run its course.” Mid recalled, “When I was very young, I know that I did the scalp injections.” These responses link to Type of Coping Strategy 1 (Physiological) that scalp injections were not the treatment of choice, *I have gotten scalp injections for my AA* (37% agree/strongly agree). Creams, lotions, and solutions were also used by the participants but were discontinued to no avail. MacDonald Hull et al. (2003) contend that even though some treatments can stimulate hair growth, the results are not long lasting. Emn tried a squaric acid solution but had a bad reaction. She then tried Rogaine and states, “That worked a lot”. Of the two participants who grew hair, it is difficult to determine what, if any, treatment triggered the growth. This coincides with the research findings that the effectiveness of these common treatments are in question (Mukherjee et al., 2009). These comments are linked to Type of Coping Strategy 1 (Physiological) *I have used prescription creams* (68% agree/strongly agree).

Results from the survey relative to Type of Coping Strategy 1 (Physiological) indicates that participants having AA for a shorter duration tried treatments more often than those who had AA for a longer duration. The results also verify that the older aged participants tried more treatments than the younger group. This could be due to the fact that younger participants are not able to make treatment choices and that parental guidance is needed.

Alternative treatments were also attempted. A few participants tried alternatives. Des “tried to go gluten free.” Emn tried “quite a few shampoos and conditioners just to try and thicken my hair.” She also started taking more vitamins. Stz tried biotin shampoos and biotin pills but neither worked for her. Type of Coping Strategy 1 (Physiological) supported these statements, *I have tried different types of shampoos* (53% agree/strongly agree) and *I have tried different types of diets to grow hair* (29% agree/strongly agree). Several mentioned the use of sun screen. Welsh and Guy (2009) commented that medical practitioners often advise using shampoos and creams as treatments. Tosti and Gray (2007) also suggest using shampoos and conditioners to improve the appearance of hair.

The literature review found hair pieces to be the cover-up most commonly used (Hunt & McHale, 2005a). All female participants indicated that they had a hair piece, but only three wore them on a daily basis. Most had a variety of options to choose from depending on the circumstance. Dey wore bandanas or hats. Mig wore a hair piece or a modified headband for dance. Emn wore hair pieces to “make my hair look thicker.” Lah wore hair pieces and a special synthetic wig for swimming. Stz was more comfortable with her hair loss and stated, “I wear hats in school . . . I occasionally walk out of the house and just, go all bald, I just don’t really care.” Type of Coping Strategy 2 (Cover-up/Avoidance) supports the fact that cover-ups were used, but not extensively, *I wear hairpieces (wigs) all the time* (28% agree/strongly agree) and *I wear hats/scarves etc. to disguise my hair loss* (47% agree/strongly agree). This could be linked to Impact

Factor 3 (Appearance/Acceptance) that most of the participants had accepted their hair loss (72%) and were okay with the way they looked (66%).

Most of the males wore caps, especially to cover from the sun or just went bald. Des was the only male who had a wig to wear for “Special occasions, like if we are going out to the theatre or a concert.”

Make-up was not often used by the participants in this study. This is probably related to their age and that males were also part of this study and females are generally the ones who use make-up. Only one interviewee, Emn, used make-up as a cover-up to “Take people away from looking at my hair.” The survey results again support the fact that make-up was not often used, *I use make-up (eyeliner, etc.) to disguise my AA* (28% agree/strongly agree).

Results from the survey relative to Type of Coping Strategy 2 (Cover-up/Avoidance), indicates that females used cover-up more often than males. Older participants and participants who developed AA later were also more likely to use a cover-up strategy.

None of the interviewees expressed any desire to join a support group or attend a conference except the three who were interviewed at the conference. Welsh and Guy (2009) found that individuals reported both negative and positive experiences with support groups. Some found them depressing. Children who attended the NAAF conference found the experience safe and comforting knowing that they were not alone. Mak shared, “I was going to be a sophomore and the last conference was about a month before I started school and that was the last time I wore a hat.” Support groups and

conferences result in individuals being able to let down their defenses and know they are not alone (Prickitt et al., 2004).

This reluctance to use outside support was also seen in the survey data results. The younger participants were more likely to use outside support. This is probably linked to how the parents view these supports. It might be difficult to attend support groups as they may not be held locally. Conferences may not be local and may cost more than a family can afford to attend. Individual counseling may also not be the best alternative to coping. Type of Coping Strategy 3 (Outside Support) supports the fact that children and adolescents did not find this strategy beneficial, *I have attended support group meetings* (27% agree/strongly agree), *My family and I have attended a conference* (26% agree/strongly agree), and *I have had individual counseling for my AA* (22% agree/strongly agree) were not thought of as a necessary component to coping with AA. This could also be connected to the fact that family and friends provided a strong support system.

The interviewees did not explicitly share information regarding internet use as it was not included in the interview script. The father of Dey did state, while Skyping, that she had an Instagram account. However, all but the three interviewees that were interviewed at the conference were contacted and interviewed via Skype, so they did have access to the internet.

Results from the survey relative to Type of Coping Strategy 4 (Social Network), indicated that females in the mid age group were more likely to use social networking. In addition, a later onset drove participants to social networks. Types of Coping Strategy 4

(Social Network) *I use social network sites to talk about AA* (26% agree/strongly agree) indicate infrequent use of social networks.

In the survey, the Type of Coping Strategy 5 (Family Support) verified that this item received the highest percentage of respondents (98%). All of the interviewees had a strong support team of family members, church members, and friends. All interviewees reported friend and family as being essential to their growth and development while dealing with their AA. They relied on their family for emotional and tangible support. This statement is confirmed by Buri (1989) that a child's self-confidence is linked to parental support. Either a parent was present or a family member was present during the interview process. The participants spoke highly about their family, or spoke about the support they were getting. Des commented, "My family has been amazing. My church and my family are probably two of the best things that I have had." Mid shared, "If I ever wanted a new hat, my dad would buy it for me . . . My little brother gets haircuts, so he buys me hats." Mak expressed that "I get support from my friends and my family and loved ones." However, Stz commented that her mother was "a little unsure about how she feels, and takes it upon herself that it's her fault that I have lost my hair." While family support can be comforting (Welsh & Guy, 2009), it may not always be available as family members also need to adapt to the changed identity of the family member (Hunt & McHale, 2005a). NAAF (2011a) addresses parents in their brochure and comments that parents should love their children unconditionally with or without hair.

The positive comments about family can be linked to Impact Factor 1 (Confidence/Self-Esteem). The percentages in this factor may not have been as high if

the family and friend support was lacking or absent. Rumsey and Harcourt (2004) suggest that support of family and friends can improve self-esteem and promote positive social interactions.

Limitations

One of the limitations of this study was the small sample size. A larger sample size could have increased reliability (Dillman et al., 2009). The scale designed by Krejcie and Morgan (1970) suggested a sample size of 377 participants. Taking Tinsley and Tinsley's (1987) rule into account the number of subjects should have been between 280 and 560.

The low response rate in both the pilot and national survey was disappointing. Higher response rates could be facilitated by ensuring that the survey is clear and easy to complete, pre-notifying the participant, use follow-up procedures, study a problem of interest to the participants, and use of incentives (Creswell, 2008). All recommendations were used except that the incentives were not explicitly stated as part of the interview. It was sent after the fact. However, it was interesting to note that of the 11 individual interview participants only two females took the initiative to contact the researcher on their own. The other participants were connected with the researcher by a parent either at the convention or via Skype. Several parents e-mailed the researcher on behalf of their children to request the consent and assent forms and to set up a convenient time and date for their children to Skype. Two parents called the researcher to let her know the status of their availability. The parents were welcome to observe during the interview process

but were asked to refrain from guiding their child's responses. One of the older males stated that "my mother made me do this."

The Cronbach's Alpha in this survey was inadequate. Adding more questions to increase the reliability could have made the survey too long and arduous for young children to complete. Therefore, specific questions were asked with little overlap.

The lack of prior research limited the findings for the literature review. The university library specialist confirmed that articles on children and adolescents were limited. Therefore, supplemental articles were added to fill in information gaps.

This study was limited to the membership of the NAAF, which was an advantage to the researcher in that they supported the study and assisted with administering the survey. However, the disadvantage was that this sample did not represent all potential children and adolescents with AA and was sent to many people who did not fit the participant parameters. The researcher was also completely reliant on the NAAF to send the survey and follow-ups due to the confidentiality of their membership and data bases.

Managing bias with this group of young people was difficult as the researcher did not want to lose their attention or trust. When the researcher asked questions that were perceived as difficult or uncomfortable for the participant, she attempted to redirect their discomfort by either moving on to another question or by stating they were not alone and had numerous support systems that were apparent by their comments about family and friends. The researcher, also having AA and appearing bald during the interview, could have increased the objectivity of her responses by maintaining neutrality rather than

offering support. The interviewees might react differently and give different responses to an interviewer with hair. This area needs further research.

Having AU gave the researcher the ability to gather observational data and ask questions that someone without this condition may overlook. However, bias may have occurred as the researcher was personally familiar with the condition and was able to confirm the respondent's answers while adding points of view and identifying with their concerns.

Recommendations

Several groups of people can benefit from the results of this survey:

(a) physicians, (b) teachers, (c) parents, and (d) the community. Children and adolescents just want to be supported, not singled out. They would like a cure for this unpredictable condition, but not a treatment that would have to be administered daily for the rest of their lives with questionable side effects. Children and adolescents need help getting the word out that this is not a life threatening or contagious disease, just one that changes their appearance.

Dermatologists are usually the first line of defense when an individual begins losing their hair. These medical professionals need to be aware of community resources such as counseling centers and support groups for their patients with AA. They should also have information on national organizations. Although securing an appointment with a dermatologist may take weeks or months, it would be prudent for these professionals to respond quickly in order to reduce the anxiety and stress that hair loss can cause.

Treatment options should be given with the premise that there is no known cure and that coping strategies may be the way to go.

Teachers and school faculty should be given tools to support their students with AA. NAAF has a School Pack that includes a DVD called “Why My Hair Falls Out” as well as brochures that explain this condition. A letter can be read to classmates the first day of school. Schools should also campaign against bullying as almost half of the respondents in the survey had been bullied. Some schools also need to relax their no hats and headwear policies or use a 504 Plan to facilitate this accommodation as AA is a physical impairment.

Parents may have a difficult time dealing with a child or adolescent with AA and may initially need resources and support. However, they must not lose sight of the fact that AA is not a life threatening condition. Children are resilient and take cues from those around them. Maintaining a sense of normalcy would be prudent. Parents can send a letter to their child’s school explaining AA. Support groups can help families realize that they are not alone in helping their child manage their AA. NAAF has set up message boards, a Pen Pal program, Facebook, and Twitter accounts that are available for connecting with others with this condition.

It is essential for the community at large to show support and accept individuals who look different. Community members can teach others how to respond by their supportive actions. Knowledge and awareness are vital. It is fortunate that there are influential individuals with AA like Charles Villanueva (NBA player) and Kayla Martel

(Miss Delaware 2010) who are positive role models and volunteer their time to create awareness.

Future Research

While formulating the survey, research indicated numerous coping strategies (refer back to Table 2). The survey was then created to include many of these strategies. However, when validating the survey, the children and adolescents were somewhat confused or unaware of many of the alternative treatments. For example, PUVA was not a treatment any of them had heard of, and hypnosis and acupuncture did not even seem as viable alternatives, therefore, those questions were eliminated from the final version of the survey. It became clear that there was limited research on children and adolescents with AA. There is a need for more research on children and adolescents to assess the strategies that are more common to that group. Several questions need to be considered in order to duplicate this study. Can the researcher be certain that the survey was taken only once by a participant? This potential problem could be remedied by giving the participant an access code to take the survey. However, the participant in this case may not feel confident that it will be anonymous. Also, how can the researcher guarantee that the responses of children 10-19 years old have answered the questions independently without the input or influence of a parent or guardian? In order to encourage independent responses without undue interference, computers could be set up at a NAAF annual conference for survey completion. The area could be roped off so that the children would be sitting at the computers within eye sight of, but away from their parent/guardian. A paper copy of the survey could be given to the parent/guardian so that they could see the

questions their children are answering. In this scenario, the consent/assent would not be embedded into the survey, but completed prior to access to the computer. In addition, the survey questions would need to be refined to increase the internal consistency of the tool. In order to accomplish this, some questions may have to be eliminated and others may need to be asked as a reverse response. It may be possible to split the instrument into two parts (e.g., factors, coping strategies) to balance the need for additional questions to address the reliability issues without lengthening the survey too much.

Female-only research could generate more detailed information regarding impact and coping strategies used. Females have more options than males regarding cover-ups, but these options are not always comfortable, affordable, or functional. Emotional issues and support appeared to impact females more than their male counterparts. Prior research indicates that females have greater difficulty with hair loss in dealing with social and self-image issues (Gallagher, 1997; Liakopoulou et al., 1997).

Several parents approached the researcher asking about a parent survey. A parent's perspective on how they manage with a child with AA could be insightful. This could help alleviate fears or concerns for parents of newly diagnosed children.

A study of young adults in their 20s could also produce helpful information. The individuals in this age group are no longer under parental control. They are beginning their careers, traveling, dating, marrying, and possibly starting families and having AA may impact these areas. In addition, interviewing and interpreting data from the younger participant was more difficult than with the older participants. They were not able to express themselves as clearly and completely as the older participants. All participants

were at different places in their lives with different goals, challenges, and pressures. The older teens were able to give a better picture of who they were with this condition and, therefore, appeared more challenged by this condition.

A researcher unfamiliar or not personally connected with this condition may look at children and adolescents with AA in a different light and may ask different questions without assuming feelings and interpretation of responses the same way a researcher with AA would. However, only future research would indicate if children and adolescents with AA would talk openly about their condition to someone who does not present with the diagnosis.

A focus group did not materialize. This could have enriched the qualitative data as the members of the group would have been able to discuss the questions in more detail playing off one another. A focus group could have provided multiple perspectives of individuals living a similar experience (Glesne, 2006).

The mention of incentives was not included in the survey invitation letter. However, a token of appreciation was either given to or mailed to those children and/or adolescents who actively participated in the follow-up interview. Many were pleasantly surprised and thanked the researcher via e-mail. Enticing individuals to participate in an individual interview was difficult and perhaps more individuals would have been willing to participate if some type of compensation was disclosed ahead of time. For instance, a statement could accompany the question at the end of the survey asking for volunteers which would simply state that for their participation, they will be given a token of

appreciation at the end of the interview. Similarly, a raffle entry option could have been offered for completion of the survey itself in an effort to increase response rate.

Final Remarks

We now know that family and friend support are vital for children and adolescents when dealing with AA. They affect the confidence and self-esteem of these individuals which can, in turn, lead to positive relationships. The duration of AA did not have any effect on the factors that impact children and adolescents. However, those who were newly diagnosed used various treatments in the hopes of growing their hair back. The younger aged participants had a higher level of confidence and were impacted less by psychological effects than the mid and older aged participants. Those participants developing AA later in life also had more difficulty in adjusting to their new appearance than those developing AA earlier in life. Females had a more difficult time adjusting to and managing AA than their male counterparts. However, females reported using more cover-ups in dealing with AA and used social networking as ways to cope.

The majority of these children and adolescents are healthy and living normal lives. The participants in this study acknowledged that there were some episodes in their lives that were more difficult to deal with than others due to their AA. While strangers often stared at their appearance, these children and adolescents reported being generally accepted by their peers and their community. While AA is not a debilitating condition, it can affect the self-esteem and identity of children and adolescents. Their attitude and ability to adjust in today's society may not only be due to the fact that they have support of family and friends but also anti-bullying campaigns. Bullying can be prevented, but

will take the power of the community working together (Stopbullying.gov, 2014). There is a trend toward treating bullying as a criminal offense (Weigel, 2012). Tolerance on various social issues seems to be on the rise from anti-bullying campaigns to same sex marriages. Young people today have a greater tolerance for differences than past generations (The Pew Research Center, 2007). Research also suggests that tolerance can be taught (Avery, Bird, Johnstone, Sullivan, & Thalhammer, 1992; Godwin, Ausbrooks, & Martinez, 2001).

All participants engaged in extracurricular activities, were able to make friends, and live their lives. AA did not seem to cause any undue interruptions in their life style. Stz stated that she was okay when she would wear hats in school and, “My friends usually rip them off my head and run down the hallway with them.” Nan stated that if her hair were to come back, “I would not know what to do with it.”

This study has advanced the understanding of how alopecia areata affects children and adolescents. However, there needs to be a greater awareness in order for those in society not to misinterpret why a person has no hair. All participants promoted awareness which could help empower the next generation of “alopecians”.

Understanding and exposure to a disability or physical impairment could increase acceptance from others (Hurst, Corning, & Ferrante, 2012).

Final words are from Shakespeare:
In nature there's no blemish but the mind;
None can be called deformed but the unkind:
Virtue is beauty, but the beauteous evil
Are empty trunks, o'erflourished by the devil.
(Twelfth Night, Act III, Scene 4)

APPENDICES

Appendix A

From: Laura Ralph
Sent: Wednesday, January 30, 2013 4:39 PM
To: Jan Wolf
Subject: Statement

Hi Jan,
The National Alopecia Areata Foundation approves of the research project you started in 2012 continuing into 2013. We are happy to access our database on your behalf to further your research project.

Please let me know if you have any questions.

Laura Ralph

National Alopecia Areata Foundation
14 Mitchell Boulevard
San Rafael, CA 94903-2050
Phone:415-472-3780
Fax:415-472-5343
www.naaf.org

Appendix B

Preteens and Teens:

You have been invited to complete this survey as part of my research study on the effects of alopecia areata (AA) on children and teenagers. I have alopecia universalis and began losing my hair when I was in my twenties. This survey, 56 questions, should only take about 15 minutes of your time, and may help others to understand how you deal with your hair loss. The National Alopecia Areata Foundation has given me permission to conduct this survey. All information will remain private.

It is important that only preteens and teens with AA between the ages of 10-19 complete this survey. In addition, before you can take this survey a consent form needs to be checked by your parents (if you are under age 18) and the assent form needs to be checked by you.

Thank you for your help!

(Click to begin survey)

Janice J. Wolf



Appendix C

Consent/Assent Documents

Informed Consent (Parent)

Research: *Children and adolescents with alopecia areata: impact factors and coping strategies used as a result of an altered appearance*

RESEARCH PROCEDURES

This research is being conducted to determine how AA affects children and adolescents as well as the coping strategies they use. You and your child are volunteering to participate in a follow-up focus group which may include 4 to 6 participants with alopecia areata or an individual interview and will take between 30 minutes to an hour. The focus group will be both audio and video recorded. The individual interview will only be audio recorded.

RISKS

There are no foreseeable risks for participating in this research. The foreseeable discomforts may relate to the types of questions to be asked about the effects of this medical condition on your child. The goal is to get a better picture as to how this condition has affected your child, but they may experience embarrassment or uneasiness when reflecting upon their feelings about this condition. Otherwise, there are no potential physical, social, or legal risks to your child in this study.

BENEFITS

There are no benefits to you or your child as a participant other than to promote further research in the area of alopecia areata and the affect it has on children and adolescents. Future researchers will benefit from understanding how this condition impacts young people's lives. They will then be able to identify factors that impact children and adolescents and coping strategies used to treat future young people with alopecia areata.

CONFIDENTIALITY

The data in this study will be confidential. Confidentiality will be maintained as your child will not be asked personal information and information gained will remain anonymous. For all written documents, the researcher will refer to the participants with either a number or pseudonym. All identifying information will be kept private, and all data will be locked in a safe location.

PARTICIPATION

Your child's participation is voluntary, and your child may withdraw from the study at any time and for any reason without any repercussion. If your child decides not to

participate or if they withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled and there will be no repercussion. There are no costs to you or any other party.

CONTACT

This research is being conducted by Janice J. Wolf, a Ph.D. candidate at George Mason University. She may be reached at (xxx) xxx-xxxx or her dissertation director, Dr. Pamela Hudson Baker (xxx) xxx-xxxx for questions or to report a research-related problem. You may contact the George Mason University Office of Research Subject Protections at (xxx) xxx-xxxx if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and give consent for my child to participate in this study.

Signature

Date of Signature

If you would like your child to be a participant in the follow-up focus group, please check ONE of the responses below:

_____ I agree to an audio and video recording of my child

_____ I do not agree to an audio and video recording of my child

OR

If you would like your child to be a participant in a follow-up individual interview, please check ONE of the responses below:

_____ I agree to an audio recording of my child

_____ I do not agree to an audio recording of my child

Informed Assent (Child or Adolescent)

Research: *Children and adolescents with alopecia areata: impact factors and coping strategies used as a result of an altered appearance*

RESEARCH PROCEDURES

This research is being done to study how children and teenagers deal with alopecia areata (AA), and how it makes them feel. You are volunteering to be part of a small group talk which will include about 4 to 6 people like yourself with AA or an individual interview and will take about 30 minutes to an hour. The group talk will be audio and video recorded. The individual interview will only be audio recorded.

RISKS

There are no known risks for participating in this research. The researcher may need to ask some personal questions about your AA, like: Does anyone else in your family have AA? Or, how does losing your hair make you feel?

BENEFITS

There are no benefits to you being part of this study other than to help give information on your feelings about having AA. Future researchers will then be able to find out more about how children and teenagers feel about AA and the things they do to help them deal with AA.

CONFIDENTIALITY

The information in this study will be kept secret. Private information will not be asked. Information from the group talk will also remain secret. You will be given a number or a fake name. All information will be kept private and will be locked up in a safe location.

PARTICIPATION

Taking part in this study is your choice. If you decide not to be part of this study, you can quit at any time. Nothing will happen if you decide not to take part in this study.

CONTACT

This research is being conducted by Janice J. Wolf, a Ph.D. candidate at George Mason University. She may be reached at (xxx) xxx-xxxx or her dissertation director, Dr. Pamela Hudson Baker (xxx) xxx-xxxx for questions or problems. You may contact the George Mason University Office of Research Subject Protections at (xxx) xxx-xxxx if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree to participate in this study.

Signature

Date of Signature

If you would like to be a part of the group talk, please check ONE of the lines below:

☐ I agree to be audio and video recorded

☐ I do not agree to be audio and video recorded

OR

If you would like to take part in an individual interview, please check ONE of the lines below:

☐ I agree to be audio recorded

☐ I do not agree to be audio recorded

Informed Consent (18 and 19 year olds)

Research: *Children and adolescents with alopecia areata: impact factors and coping strategies used as a result of an altered appearance*

RESEARCH PROCEDURES

This research is being conducted to determine how AA affects children and adolescents as well as the coping strategies they use. You are volunteering to participate in a follow-up focus group which may include 4 to 6 participants with alopecia areata or an individual interview and will take between 30 minutes to an hour. The focus group will be both audio and video recorded. The individual interview will only be audio recorded.

RISKS

There are no foreseeable risks for participating in this research. The foreseeable discomforts may relate to the types of questions to be asked about the effects of this medical condition on you. The goal is to get a better picture as to how this condition has affected you, and you may experience embarrassment or uneasiness when reflecting upon your feelings about this condition. Otherwise, there are no potential physical, social, or legal risks to you in this study.

BENEFITS

There are no benefits to you as a participant other than to promote further research in the area of alopecia areata and the affect it has on children and adolescents. Future researchers will benefit from understanding how this condition impacts young people's lives. They will then be able to identify factors that impact children and adolescents and coping strategies used to treat future young people with alopecia areata.

CONFIDENTIALITY

The data in this study will be confidential. Confidentiality will be maintained as you will not be asked personal information and information gained will remain anonymous. For all written documents, the researcher will refer to the participants with either a number or pseudonym. All identifying information will be kept private, and all data will be locked in a safe location.

PARTICIPATION

Your participation is voluntary, and you may withdraw from the study at any time and for any reason without any repercussion. If you decide not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled and there will be no repercussion. There are no costs to you or any other party.

CONTACT

This research is being conducted by Janice J. Wolf, a Ph.D. candidate at George Mason University. She may be reached at (xxx) xxx-xxxx or her dissertation director, Dr.

Pamela Hudson Baker (xxx) xxx-xxxx for questions or to report a research-related problem. You may contact the George Mason University Office of Research Subject Protections at (xxx) xxx-xxxx if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree to participate in this study.

_____ Signature	_____ Date of Signature
--------------------	----------------------------

If you would like to be a participant in the follow-up focus group, please check ONE of the responses below:

- ☐ I agree to be audio and video recorded
☐ I do not agree to be audio and video recorded

OR

If you would like to be a participant in a follow-up individual interview, please check ONE of the responses below:

- ☐ I agree to be audio recorded
☐ I do not agree to be audio recorded

Appendix D

Pilot Consent/Assent

Informed Consent (Parent)

Research: *Children and adolescents with alopecia areata: impact factors and coping strategies used as a result of an altered appearance*

RESEARCH PROCEDURES

This research is being conducted to determine how AA affects children and adolescents as well as the coping strategies they use. A 56 question survey with a four point rating scale will be used to assess the factors that impact your child/adolescent and the coping strategies they use to manage their AA. Once you and your child have agreed to this research study, you will have access to the electronic survey. This survey should take about 15 minutes to complete and all answers will remain anonymous. While it is understood that no computer transmission can be perfectly secure, reasonable efforts will be made to protect the confidentiality of your transmission. At the end of the survey, your child will also be asked to volunteer in a follow-up focus group which may include 4 to 6 participants with alopecia areata or an individual interview and will take between 30 minutes to an hour. Date and time of the focus group or individual interview will be determined by the researcher after participants have been screened. The focus group will be both audio and video recorded. The individual interview will only be audio recorded.

RISKS

There are no foreseeable risks for participating in this research. The foreseeable discomforts may relate to the types of questions to be asked about the effects of this medical condition on your child. The goal is to get a better picture as to how this condition has affected your child, but they may experience embarrassment or uneasiness when reflecting upon their feelings about this condition. Otherwise, there are no potential physical, social, or legal risks to your child in this study.

BENEFITS

There are no benefits to you or your child as a participant other than to promote further research in the area of alopecia areata and the affect it has on children and adolescents. Future researchers will benefit from understanding how this condition impacts young people's lives. They will then be able to identify factors that impact children and adolescents and coping strategies used to treat future young people with alopecia areata.

CONFIDENTIALITY

The data in this study will be confidential. Confidentiality will be maintained by giving your child an electronic link to the survey. Identifying information will not be

asked in the survey and if your child is willing to participate in the follow-up focus group or individual interview, they will be directed to another link in order to respond directly to the researcher. The information gained from the follow-up focus group or individual interview will also remain anonymous. For all written documents, the researcher will refer to the participants with either a number or pseudonym. All identifying information will be kept private, and all data will be locked in a safe location.

PARTICIPATION

Your child's participation is voluntary, and your child may withdraw from the study at any time and for any reason without any repercussion. If your child decides not to participate or if they withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled and there will be no repercussion. There are no costs to you or any other party.

CONTACT

This research is being conducted by Janice J. Wolf, a Ph.D. candidate at George Mason University. She may be reached at (xxx) xxx-xxxx or her dissertation director, Dr. Pamela Hudson Baker (xxx) xxx-xxxx for questions or to report a research-related problem. You may contact the George Mason University Office of Research Subject Protections at (xxx) xxx-xxxx if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree for my child to participate in this study on children and adolescents with alopecia areata. The George Mason University Human Subjects Review Board has waived the requirement for a signature on this consent form. However, if you wish to sign a consent form, please contact Janice Wolf at: xxxx

[] Please click here to give consent for your child to participate in this study.

Informed Assent (Child or Adolescent)

Research: *Children and adolescents with alopecia areata: impact factors and coping strategies used as a result of an altered appearance*

RESEARCH PROCEDURES

This research is being done to study how children and teenagers deal with alopecia areata (AA), and how it makes them feel. A 56 question survey with a four point rating scale will be used to find out how children and teenagers feel about their hair loss and how they deal with their hair loss. Once you have agreed to help in this research, you will be able to take the survey on-line. This survey should take about 15 minutes to finish and all of your answers will be kept secret. We will do our best to make sure your information is protected when you take the on-line survey. At the end of the survey you will also be asked if you want to be part of a small group talk which will include about 4 to 6 people like yourself with AA or an individual interview that will take about 30 minutes to an hour. The date and time of the group talk or individual interview will be put together by the researcher. She will call or e-mail you and your parent/guardian with the information. The group talk will be audio and video recorded. The individual interview will only be audio recorded.

RISKS

There are no known risks for taking part in this research. The researcher may need to ask some personal questions about your AA, like: Does anyone else in your family have AA? Or, how does losing your hair make you feel?

BENEFITS

There are no benefits to you being part of this study other than to help give information on your feelings about having AA. Future researchers will then be able to find out more about how children and teenagers feel about AA and the things they do to help them deal with AA.

CONFIDENTIALITY

The information in this study will be kept secret. You will be given a link to the survey on-line. Private information will not be asked in the survey. If you want to join in on the group talk or individual interview, you and your parent/guardian will be asked to go to another site to contact the researcher. Information from the group talk will also remain secret. You will be given a number or a fake name. All information will be kept private and will be locked up in a safe location.

PARTICIPATION

Taking part in this study is your choice. If you decide not to be part of this study, you can quit at any time. Nothing will happen if you decide not to take part in this study.

CONTACT

This research is being conducted by Janice J. Wolf, a Ph.D. candidate at George Mason University. She may be reached at (xxx) xxx-xxxx or her dissertation director, Dr. Pamela Hudson Baker (xxx) xxx-xxxx for questions or problems. You may contact the George Mason University Office of Research Subject Protections at (xxx) xxx-xxxx if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree to participate in this study on children and adolescents with alopecia areata. You do not need to sign this form, but if you want a copy to sign I can send you one. Please contact me at: xxxx

[] Please click here if you agree to be part of this study and you will be taken to the survey.

Informed Consent (18 and 19 year olds)

Research: *Children and adolescents with alopecia areata: impact factors and coping strategies used as a result of an altered appearance*

RESEARCH PROCEDURES

This research is being conducted to determine how AA affects children and adolescents as well as the coping strategies they use. A 56 question survey with a four point rating scale will be used to assess the factors that impact you and the coping strategies you use to manage your AA. Once you have agreed to this research study, you will have access to the electronic survey. This survey should take about 15 minutes to complete and all answers will remain anonymous. While it is understood that no computer transmission can be perfectly secure, reasonable efforts will be made to protect the confidentiality of your transmission. At the end of the survey you will also be asked to volunteer in a follow-up focus group which may include 4 to 6 participants with alopecia areata or an individual interview and will take between 30 minutes to an hour. Date and time of the focus group or individual interview will be determined by the researcher after participants have been screened. The focus group will be both audio and video recorded. The individual interview will only be audio recorded.

RISKS

There are no foreseeable risks for participating in this research. The foreseeable discomforts may relate to the types of questions to be asked about the effects of this medical condition on you. The goal is to get a better picture as to how this condition has affected you, but you may experience embarrassment or uneasiness when reflecting upon your feelings about this condition. Otherwise, there are no potential physical, social, or legal risks to you in this study.

BENEFITS

There are no benefits to you as a participant other than to promote further research in the area of alopecia areata and the affect it has on children and adolescents. Future researchers will benefit from understanding how this condition impacts young people's lives. They will then be able to identify factors that impact children and adolescents and coping strategies used to treat future young people with alopecia areata.

CONFIDENTIALITY

The data in this study will be confidential. Confidentiality will be maintained by taking the survey by way of an electronic link. Identifying information will not be asked in the survey and if you are willing to participate in the follow-up focus group or individual interview, you will be directed to another link in order to respond directly to the researcher. The information gained from the follow-up focus group or individual interview will also remain anonymous. For all written documents, the researcher will refer to you with either a number or pseudonym. All identifying information will be kept private, and all data will be locked in a safe location.

PARTICIPATION

Your participation is voluntary, and you may withdraw from the study at any time and for any reason without any repercussion. If you decide not to participate or if they withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled and there will be no repercussion. There are no costs to you or any other party.

CONTACT

This research is being conducted by Janice J. Wolf, a Ph.D. candidate at George Mason University. She may be reached at (xxx) xxx-xxxx or her dissertation director, Dr. Pamela Hudson Baker (xxx) xxx-xxxx for questions or to report a research-related problem. You may contact the George Mason University Office of Research Subject Protections at (xxx) xxx-xxxx if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree to participate in this study on children and adolescents with alopecia areata. The George Mason University Human Subjects Review Board has waived the requirement for a signature on this consent form. However, if you wish to sign a consent form, please contact Janice Wolf at: xxxx

[] Please click here to give your consent to participate in this study.

Appendix E

National Consent/Assent

Informed Consent (Parent)

Research: *Children and adolescents with alopecia areata: impact factors and coping strategies used as a result of an altered appearance*

RESEARCH PROCEDURES

This research is being conducted to determine how AA affects children and adolescents as well as the coping strategies they use. A 56 question survey with a four point rating scale will be used to assess the factors that impact your child/adolescent and the coping strategies they use to manage their AA. Once you and your child have agreed to this research study, you will have access to the electronic survey. This survey should take about 15 minutes to complete and all answers will remain anonymous. While it is understood that no computer transmission can be perfectly secure, reasonable efforts will be made to protect the confidentiality of your transmission. At the end of the survey your child will also be asked to volunteer in a follow-up interview that will take between 30 minutes to an hour. Date and time will be set up that will be convenient to you, your child, and the researcher. The interview will be audio recorded and could take place by phone, Skype, or in person.

RISKS

There are no foreseeable risks for participating in this research. The foreseeable discomforts may relate to the types of questions to be asked about the effects of this medical condition on your child. The goal is to get a better picture as to how this condition has affected your child, but they may experience embarrassment or uneasiness when reflecting upon their feelings about this condition. Otherwise, there are no potential physical, social, or legal risks to your child in this study.

BENEFITS

There are no benefits to you or your child as a participant other than to promote further research in the area of alopecia areata and the affect it has on children and adolescents. Future researchers will benefit from understanding how this condition impacts young people's lives. They will then be able to identify factors that impact children and adolescents and coping strategies used to treat future young people with alopecia areata.

CONFIDENTIALITY

The data in this study will be confidential. Confidentiality will be maintained by giving your child an electronic link to the survey. Identifying information will not be asked in the survey and if your child is willing to participate in an individual interview,

they will be directed to another link in order to respond directly to the researcher. The information gained from the follow-up individual interview will also remain anonymous. For all written documents, the researcher will refer to the participants with either a number or pseudonym. All identifying information will be kept private, and all data will be locked in a safe location.

PARTICIPATION

Your child's participation is voluntary, and your child may withdraw from the study at any time and for any reason without any repercussion. If your child decides not to participate and drops out of the study, there is no penalty or loss of benefits to which you are otherwise entitled and there will be no repercussion. There are no costs to you or any other party.

CONTACT

This research is being conducted by Janice J. Wolf, a Ph.D. candidate at George Mason University. She may be reached at (xxx) xxx-xxxx or her dissertation director, Dr. Pamela Hudson Baker (xxx) xxx-xxxx for questions or to report a research-related problem. You may contact the George Mason University Office of Research Subject Protections at (xxx) xxx-xxxx if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree for my child to participate in this study on children and adolescents with alopecia areata. The George Mason University Human Subjects Review Board has waived the requirement for a signature on this consent form. However, if you wish to sign a consent form, please contact Janice Wolf at: xxxx

[] Please click here to give consent for your child to participate in this study.

Informed Assent (Child or Adolescent)

Research: *Children and adolescents with alopecia areata: impact factors and coping strategies used as a result of an altered appearance*

RESEARCH PROCEDURES

This research is being done to study how children and teenagers deal with alopecia areata (AA), and how it makes them feel. A 56 question survey with a four point rating scale will be used to find out how children and teenagers feel about their hair loss and how they deal with their hair loss. Once you have agreed to help in this research, you will be able to take the survey on-line. This survey should take about 15 minutes to finish and all of your answers will be kept secret. We will do our best to make sure your information is protected when you take the on-line survey. At the end of the survey you will also be asked if you want to take part in an interview that will take about 30 minutes to an hour. The date and time of this interview will be put together by the researcher. She will call or e-mail you and your parent/guardian with the information. The interview will be audio recorded.

RISKS

There are no known risks for taking part in this research. The researcher may need to ask some personal questions about your AA, like: Does anyone else in your family have AA? Or, how does losing your hair make you feel?

BENEFITS

There are no benefits to you being part of this study other than to help give information on your feelings about having AA. Future researchers will then be able to find out more about how children and teenagers feel about AA and the things they do that help them deal with their AA.

CONFIDENTIALITY

The information in this study will be kept secret. You will be given a link to the survey on-line. Private information will not be asked in the survey. If you would like to take part in a follow-up individual interview, you and your parent/guardian will be asked to go to another site to contact the researcher. Information from individual interview will remain secret. You will be given a number or a fake name. All information will be kept private and will be locked up in a safe location.

PARTICIPATION

Taking part in this study is your choice. If you decide not to be part of this study, you can quit at any time. Nothing will happen if you decide not to take part in this study.

CONTACT

This research is being conducted by Janice J. Wolf, a Ph.D. candidate at George Mason University. She may be reached at (xxx) xxx-xxxx or her dissertation director, Dr. Pamela Hudson Baker (xxx) xxx-xxxx for questions or problems. You may contact the

George Mason University Office of Research Subject Protections at (xxx) xxx-xxxx if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree to participate in this study on children and adolescents with alopecia areata. You do not need to sign this form, but if you want a copy to sign I can send you one. Please contact me at: xxxx

☐ Please click here if you agree to be part of this study and you will be taken to the survey.

Informed Consent (18 and 19 year olds)

Research: *Children and adolescents with alopecia areata: impact factors and coping strategies used as a result of an altered appearance*

RESEARCH PROCEDURES

This research is being conducted to determine how AA affects children and adolescents as well as the coping strategies they use. A 56 question survey with a four point rating scale will be used to assess the factors that impact you and the coping strategies you use to manage your AA. Once you have agreed to this research study, you will have access to the electronic survey. This survey should take about 15 minutes to complete and all answers will remain anonymous. While it is understood that no computer transmission can be perfectly secure, reasonable efforts will be made to protect the confidentiality of your transmission. At the end of the survey you will also be asked to volunteer in a follow-up individual interview that will take between 30 minutes to an hour. Date and time of the individual interview will be determined by the researcher after participants have been screened. This individual interview will only be audio recorded and could take place by phone, Skype, or in person.

RISKS

There are no foreseeable risks for participating in this research. The foreseeable discomforts may relate to the types of questions to be asked about the effects of this medical condition on you. The goal is to get a better picture as to how this condition has affected you, but you may experience embarrassment or uneasiness when reflecting upon your feelings about this condition. Otherwise, there are no potential physical, social, or legal risks to you in this study.

BENEFITS

There are no benefits to you as a participant other than to promote further research in the area of alopecia areata and the affect it has on children and adolescents. Future researchers will benefit from understanding how this condition impacts young people's lives. They will then be able to identify factors that impact children and adolescents and coping strategies used to treat future young people with alopecia areata.

CONFIDENTIALITY

The data in this study will be confidential. Confidentiality will be maintained by taking the survey by way of an electronic link. Identifying information will not be asked in the survey and if you are willing to participate in the follow-up individual interview, you will be directed to another link in order to respond directly to the researcher. The information gained from the individual interview will also remain anonymous. For all written documents, the researcher will refer to you with either a number or pseudonym. All identifying information will be kept private, and all data will be locked in a safe location.

PARTICIPATION

Your participation is voluntary, and you may withdraw from the study at any time and for any reason without any repercussion. If you decide not to participate or if they withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled and there will be no repercussion. There are no costs to you or any other party.

CONTACT

This research is being conducted by Janice J. Wolf, a Ph.D. candidate at George Mason University. She may be reached at (xxx) xxx-xxxx or her dissertation director, Dr. Pamela Hudson Baker (xxx) xxx-xxxx for questions or to report a research-related problem. You may contact the George Mason University Office of Research Subject Protections at (xxx) xxx-xxxx if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree to participate in this study on children and adolescents with alopecia areata. The George Mason University Human Subjects Review Board has waived the requirement for a signature on this consent form. However, if you wish to sign a consent form, please contact Janice Wolf at: xxxx

[] Please click here to give your consent to participate in this study.

Appendix F

Alopecia Areata Survey (Prior to Validation)

Part 1: How do you feel about having AA?

Directions: Check the box that best fits who you are.

AA= Patchy Alopecia, Alopecia Totalis, Alopecia Universalis	Strongly Agree (4)	Agree (3)	Disagree (2)	Strongly Disagree (1)
1. I enjoy going out with my friends				
2. I like to wear hats/scarves/dorags/skull caps				
3. I can make friends easily				
4. I use over-the-counter medications (head oils, Minoxidil)				
5. I usually go bald during most of the day				
6. I have gone out to have head massages				
7. I have a hard time making friends				
8. I have attended support group meetings				
9. I think about my positive qualities once a day				
10. I wear hairpieces (wigs) all the time				
11. Having AA does not bother me				
12. I think wigs are fun to wear all the time				
13. I would like to have a full head of hair				
14. I use prescriptions from the doctor to help me feel better (antidepressants)				
15. I avoid being around people				

16. My teachers accept me for who I am				
17. I get along well with my family				
18. I have had PUVA treatments for my AA				
19. I often fear being rejected by others				
20. I have had individual counseling for my AA				
21. I have told my friends about my AA				
22. I wear face make-up (eyeliner, eyebrow pencil etc.)				
23. I prefer to do things by myself				
24. I get scalp injections for my AA				
25. I feel like a failure				
26. I am in special education classes because of my AA				
27. I feel that I am a special person because of my AA				
28. I have used hypnosis for my AA				
29. I am okay with the way I look				
30. My family has attended a professional conference like, the National Alopecia Areata Foundation (NAAF), Children's Alopecia Project (CAP)				
31. I enjoy hanging out at the mall with my friends				
32. I have used permanent make-up (eyeliner, eyebrows)				
33. I am afraid to tell my friends about my AA				
34. I use prescription creams (corticosteroids)				
35. Having AA makes me angry with myself				
36. I have tried different diets (diary, protein, veggie,				

meatless) to grow my hair back				
37. People have made fun of me because I am bald				
38. I have been in chat rooms on the internet to discuss AA				
39. I participate in sports with my friends				
40. I tell people about my AA if they ask				
41. I can do things as well as my peers				
42. I have looked up information and resources online about AA				
43. I think about my hair loss daily				
44. I have tried different types of shampoos and conditioners				
45. I feel that I have the same opportunities as other people				
46. I have tried acupuncture for my AA				
47. I often cry about my hair loss				
48. I have taken vitamins for my hair				
49. I have accepted my hair loss				
50. I have had surgical hair implants				
51. I have continued to live my life as it was before my AA				
52. I use social network sites to talk to friends (Facebook, Twitter)				
53. I have many good qualities				
54. My family and I have helped out at professional conferences (NAAF, CAP)				
55. I would never change the way I look				
56. My family helps me cope with my AA				

Part 2: You and Your Family

Directions: For the following questions, please check the appropriate box (one box only)

57. Your current age:

1.	<10	
2.	10	
3.	11	
4.	12	
5.	13	
6.	14	
7.	15	
8.	16	
9.	17	
10.	18	
11.	19	
12.	>19	

58. Your gender:

1.	Male	
2.	Female	

59. Your ethnic background:

1.	Caucasian	
2.	African American	
3.	Asian American	
4.	Hispanic	
5.	Other	

60. Are you a student?

1.	Yes	
2.	No	

61. I have had to change schools because of my alopecia areata

1.	Yes	
2.	No	

62. Being bullied:

1.	Yes, I have been bullied because of my hair loss	
----	--	--

2.	No, I have not been bullied because of my hair loss	
----	---	--

63. Region I live in:

1.	Northeast: ME, NH, VT, MA, RI, CT, NY, PA, NJ	
2.	Southeast: MD, DE, WV, VA, KY, TN, NC, SC, GA, FL, AL, MS, LA, AR	
3.	Midwest: OH, IN, IL, MI, WI, MN, IA, MO, KS, NE, SD, ND	
4.	Southwest: TX, OK, NM, AZ	
5.	Rocky Mountain: CO, UT, NV, MT, WY, ID	
6.	Pacific: WA, OR, CA	
7.	Noncontiguous (Alaska, Hawaii)	

64. Region location:

1.	Urban (in a large city)	
2.	Suburban (outside of a city)	
3.	Rural (in the country)	

65. My age when I was diagnosed with alopecia areata

1.	<1	
2.	1	
3.	2	
4.	3	
5.	4	
6.	5	
7.	6	
8.	7	
9.	8	
10.	9	
11.	10	
12.	11	
13.	12	
14.	13	
15.	14	
16.	15	
17.	16	
18.	17	
19.	18	
20.	19	
21.	>19	

66. My current alopecia status is:

1. I was diagnosed with alopecia areata, but my hair has grown back	
2. I was diagnosed with alopecia areata, and my hair has NOT grown back	

67. Alopecia areata family history

1. Someone in my immediate family also has alopecia areata (mom, dad, sibling)	
2. Someone in my extended family has alopecia areata (aunt, uncle, cousin)	

68. I have had alopecia areata for the following number of years:

1.	<1	
2.	1	
3.	2	
4.	3	
5.	4	
6.	5	
7.	6	
8.	7	
9.	8	
10.	9	
11.	10	
12.	11	
13.	12	
14.	13	
15.	14	
16.	15	
17.	16	
18.	17	
19.	18	
20.	19	
21.	>19	

(Pilot Study) Thank you for participating in this survey.

Would you be willing to participate in a follow-up group interview of approximately six people (30 -60 minutes)?

1. Yes
2. No

If Yes, please provide an e-mail address, phone number or both so that I can contact you:

E-mail address: _____

Phone number: _____

All information will be kept strictly confidential. If you feel more comfortable, please contact me via my e-mail address on the cover letter.

OR

(National Survey) Thank you for your participating in this survey.

Would you be willing to participate in a follow-up interview via: phone, Skype, or in person (30-60 minutes)?

1. Yes

2. No

If Yes, please provide an e-mail address, phone number or both so that I can contact you:

E-mail address: _____

Phone number: _____

Appendix G

Validation Survey Sent to NAAF Board of Directors and Children/Adolescent Panels

Part 1: Your Feelings About Alopecia Areata – Place a check mark in the box that reflects the necessity and value of the survey question

Factors that Impact AA AA= Patchy Alopecia, Alopecia Totalis, Alopecia Universalis	Essential statement to include (3)	Useful statement, but not essential to include (2)	Statement is not important to include (1)
1. I enjoy going out with my friends			
2. I like to wear hats/scarves/dorags/skull caps			
3. I can make friends easily			
4. I use over-the-counter medications (head oils, Minoxidil)			
5. I usually go bald during most of the day			
6. I have gone out to have head massages			
7. I have a hard time making friends			
8. I have attended support group meetings			
9. I think about my positive qualities daily			
10. I wear hairpieces (wigs) all the time			
11. Having AA does not bother me			
12. I think wigs are fun to wear all the time			
13. I would like to have a full head of hair			
14. I use prescriptions from the doctor to help me			

feel better (antidepressants)			
15. I avoid being around people			
16. My teachers accept me for who I am			
17. I get along well with my family			
18. I have had PUVA treatments for my AA			
19. I often fear being rejected by others			
20. I have had individual counseling for my AA			
21. I have told my friends about my AA			
22. I wear face make-up (eyeliner, eyebrow pencil etc.)			
23. I prefer to do things by myself			
24. I get scalp injections for my AA			
25. I feel like a failure			
26. I am in special education classes because of my AA			
27. I feel that I am a special person because of my AA			
28. I have used hypnosis for my AA			
29. I am okay with the way I look			
30. My family has attended a professional conference like, the National Alopecia Areata Foundation (NAAF), Children's Alopecia Project (CAP)			
31. I enjoy hanging out at			

the mall with my friends			
32. I have used permanent make-up (eyeliner, eyebrows)			
33. I am afraid to tell my friends about my AA			
34. I use prescription creams (corticosteroids)			
35. Having AA makes me angry with myself			
36. I have tried different diets (diary, protein, veggie, meatless) to grow my hair back			
37. People have made fun of me because I am bald			
38. I have been in chat rooms on the internet to discuss AA			
39. I participate in sports with my friends			
40. I tell people about my AA if they ask			
41. I can do things as well as my peers			
42. I have looked up information and resources online about AA			
43. I think about my hair loss daily			
44. I have tried different types of shampoos and conditioners			
45. I feel that I have the same opportunities as other people			
46. I have tried acupuncture for my AA			

47. I often cry about my hair loss			
48. I have taken vitamins for my hair			
49. I have accepted my hair loss			
50. I have had surgical hair implants			
51. I have continued to live my life as it was before my AA			
52. I use social network sites to talk to friends (Facebook, Twitter)			
53. I have many good qualities			
54. My family and I have helped out at professional conferences (NAAF, CAP)			
55. I would never change the way I look			
56. My family helps me cope with my AA			

Part 2: You and Your Family – Place a check mark in the box that reflects the necessity and value of the survey question.

Demographics AA= Patchy Alopecia, Alopecia Totalis, Alopecia Universalis	Essential statement to include (3)	Useful statement, but not essential to include (2)	Statement is not important to include(1)
57. Your age			
58. Your gender			
59. Your ethnic background			
60. Are you a student? Y/N			

61. Have you had to change schools because of your AA?			
62. Have you been bullied? Y/N			
63. U.S. Region you live in (NE, SE, Midwest, SW, Rocky Mt., Pacific, Noncontiguous)			
64. Physical location (urban, suburban, rural)			
65. Age when you were first diagnosed with AA			
66. Current status with AA (hair has grown back, hair has not grown back)			
67. AA family history (someone in immediate family has AA (mom, dad, sibling) or someone in your extended family has AA (aunt, uncle, cousin)			
68. Number of years you have had AA			

Are there any questions that you feel should be added?

Appendix H

Validation Survey Results

Sent to NAAF Board of Directors and Children/Adolescent Panels

The ratio (# / #) represents the number of Board members responding to the question followed by the number of children/adolescents responding to the question. The first percentage is the percentage of Board members who selected the statement followed by the percentage of children/adolescents selecting the statement.

Part 1: Your Feelings About Alopecia Areata – Place a check mark in the box that reflects the necessity and value of the survey question

Factors that Impact AA AA= Patchy Alopecia, Alopecia Totalis, Alopecia Universalis	Essential statement to include (3)	Useful statement, but not essential to include (2)	Statement is not important to include (1)
1. I enjoy going out with my friends	4/3 80% / 75%	1/1 20% / 25%	0/0
2. I like to wear hats/scarves/do-rags/skullcaps	4/2 80% / 50%	0/1 0% / 25%	1/1 20% / 25%
3. I can make friends easily	4/1 80% / 25%	1/2 20% / 50%	0/1 0% / 25%
4. I use over-the-counter medications (head oils, Minoxidil)	0/0	4/2 80% / 50%	1/2 20% / 50%
5. I usually go bald during most of the day	3/1 60% / 25%	2/1 40% / 25%	0/2 0% / 50%
6. I have gone out to have head massages	1/0 20% / 0%	1/1 20% / 25%	3/3 60% / 75%
7. I have a hard time making friends	3/1 60% / 25%	1/2 20% / 50%	1/1 20% / 25%
8. I have attended support group meetings	4/3 80% / 75%	1/0 20% / 0%	0/1 0% / 25%
9. I think about my	2/2	3/1	0/1

positive qualities once a day	40% / 50%	60% / 25%	0% / 25%
10. I wear hairpieces (wigs) all the time	3/2 60% / 50%	2/2 40% / 50%	0/0
11. Having AA does not bother me	5/3 100% / 75%	0/0	0/1 0% / 25%
12. I think wigs are fun to wear all the time	2/1 40% / 25%	3/2 60% / 50%	0/1 0% / 25%
13. I would like to have a full head of hair	4/3 80% / 75%	1/1 20% / 25%	0/0
14. I use prescriptions from the doctor to help me feel better (antidepressants)	4/1 80% / 25%	0/1 0% / 25%	1/2 20% / 50%
15. I avoid being around people	4/1 80% / 25%	0/3 0% / 75%	1/0 20% / 0%
16. My teachers accept me for who I am	5/3 100% / 75%	0/1 0% / 25%	0/0
17. I get along well with my family	4/2 80% / 50%	1/2 20% / 50%	0/0
18. I have had PUVA treatments for my AA	1/0 20% / 0%	4/2 80% / 50%	0/2 0% / 50%
19. I often fear being rejected by others	4/3 80% / 75%	0/1 0% / 25%	1/0 20% / 0%
20. I have had individual counseling for my AA	4/1 80% / 25%	0/2 0% / 50%	1/1 20% / 25%
21. I have told my friends about my AA	5/3 100% / 75%	0/1 0% / 25%	0/0
22. I wear face make-up (eyeliner, eyebrow pencil etc.) to disguise my hair loss	2/1 40% / 25%	3/2 60% / 50%	0/1 0% / 25%
23. I prefer to do things by myself	3/2 60% / 50%	0/2 0% / 50%	2/0 40% / 0%
24. I get scalp injections for my AA	1/3 20% / 75%	4/1 80% / 25%	0/0
25. I feel like a failure	3/1	0/2	2/1

	60% / 25%	0% / 50%	40% / 25%
26. I am in special education classes because of my AA	4/0 80% / 0%	0/2 0% / 50%	1/2 20% / 50%
27. I feel that I am a special person because of my AA	5/1 100% / 25%	0/3 0% / 75%	0/0
28. I have used hypnosis for my AA	2/1 40% / 25%	3/2 60% / 50%	0/1 0% / 25%
29. I am okay with the way I look	5/3 100% / 75%	0/0	0/1 0% / 25%
30. My family has attended a professional conference like, the National Alopecia Areata Foundation (NAAF), Children's Alopecia Project (CAP)	2/1 40% / 25%	2/2 40% / 50%	1/1 20% / 25%
31. I enjoy hanging out at the mall with my friends	2/4 40% / 100%	2/0 40% / 0%	1/0 20% / 0%
32. I have used permanent make-up (eyeliner, eyebrows) to disguise my hair loss	2/2 40% / 50%	3/2 60% / 50%	0/0
33. I am afraid to tell my friends about my AA	4/3 80% / 75%	0/1 0% / 25%	1/0 20% / 0%
34. I use prescription creams (corticosteroids)	1/1 20% / 25%	4/2 80% / 50%	1/1 20% / 25%
35. Having AA makes me angry with myself	4/0 80% / 0%	0/3 0% / 75%	1/1 20% / 25%
36. I have tried different diets (diary, protein, veggie, meatless) to grow my hair back	1/1 20% / 25%	4/3 80% / 75%	0/0

37. People have made fun of me because I am bald	5/4 100% / 100%	0/0	0/0
38. I have been in chat rooms on the internet to discuss AA	3/1 60% / 25%	1/2 20% / 50%	1/1 20% / 25%
39. I participate in sports with my friends	2/4 40% / 100%	3/0 60% / 0%	0/0
40. I tell people about my AA if they ask	4/3 80% / 75%	1/0 20% / 0 %	0/1 0% / 25%
41. I can do things as well as my peers	4/3 80% / 75%	2/0 40% / 0%	0/0
42. I have looked up information and resources online about AA	3/4 60% / 100%	2/0 40% / 0%	0/0
43. I think about my hair loss daily	5/3 100% / 75%	0/1 0% / 25%	0/0
44. I have tried different types of shampoos and conditioners	2/2 40% / 50%	3/1 60% / 25%	0/1 0% / 25%
45. I feel that I have the same opportunities as other people	5/3 100% / 75%	0/1 0% / 25%	0/0
46. I have tried acupuncture for my AA	1/1 20% / 25%	4/1 80% / 25%	0/2 0% / 50%
47. I often cry about my hair loss	4/2 80% / 50%	0/1 0% / 25%	1/1 20% / 25%
48. I have taken vitamins for my hair	1/2 20% / 50%	4/1 80% / 25%	0/1 0% / 25%
49. I have accepted my hair loss	5/3 100% / 75%	0/0	0/1 0% / 25%
50. I have had surgical hair implants	0/2 0% / 50%	4/1 80% / 25%	1/1 20% / 25%
51. I have continued to live my life as it was before my AA	4/3 80% / 75%	1/1 20% / 25%	0/0
52. I use social network sites to talk to friends (Facebook, Twitter)	4/2 80% / 50%	1/0 20% / 0%	0/2 0% / 50%

53. I have many good qualities	4/2 80% / 50%	1/1 20% / 25%	0/1 0% / 25%
54. My family and I have helped out at professional conferences (NAAF, CAP)	2/1 40% / 25%	2/1 40% / 25%	1/2 20% / 50%
55. I would never change the way I look	3/3 60% / 75%	2/0 40% / 9%	0/1 0% / 25%
56. My family helps me cope with my AA	3/3 60% / 75%	2/1 40% / 25%	0/0

Part 2: You and Your Family – Place a check mark in the box that reflects the necessity and value of the survey question. Due to incorrectly answered questions only a combined percentage was calculated and placed next to the question.

Demographics AA= Patchy Alopecia, Alopecia Totalis, Alopecia Universalis	Essential statement to include (3)	Useful statement, but not essential to include (2)	Statement is not important to include(1)
57. Your age (75%)	4/2	0/2	0/0
58. Your gender (88%)	4/3	0/1	0/0
59. Your ethnic background (50%)	3/1	0/3	1/0
60. Are you a student? Y/N (88%)	3/4	1/0	0/0
61. Have you had to change schools because of your AA? (88%)	4/3	0/0	0/1
62. Have you been bullied because of AA? Y/N (88%)	3/4	1/0	0/0
63. U.S. Region you live in (NE, SE, Midwest, SW, Rocky Mt., Pacific, Noncontiguous) (50%)	3/1	1/3	0/0

64. Physical location (urban, suburban, rural) (75%)	3/3	1/1	0/0
65. Age when you were first diagnosed with AA (100%)	4/4	0/0	0/0
66. Current status with AA (hair has grown back, hair has not grown back) (100%)	4/4	0/0	0/0
67. AA family history (someone in immediate family has AA (mom, dad, sibling) or someone in your extended family has AA (aunt, uncle, cousin) 88%)	3/4	1/0	0/0
68. Number of years you have had AA (100%)	4/4	0/0	0/0

Appendix I

Validated Survey

Part 1: How do you feel about having alopecia areata?

Directions: Check the box that best fits who you are.

Alopecia areata = Patchy Alopecia, Alopecia Totalis, Alopecia Universalis	Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)
1. My family helps support me with my alopecia areata				
2. I enjoy going out with my friends				
3. I can make friends easily				
4. I wear hats/scarves/do-rags/skull caps to disguise my hair loss				
5. I usually go bald during most of the day				
6. I think about my positive qualities once a day				
7. I use prescriptions from the doctor to help me feel better about my hair loss				
8. Having alopecia areata does not bother me				
9. I would like to have a full head of hair				
10. I have had individual counseling for my alopecia areata				
11. My teachers accept me for who I am				
12. I avoid being around people because of my hair loss				
13. I use make-up (eyeliner, eyebrow pencil, etc.) to disguise my hair loss				
14. I get along well with my				

family				
15. I often fear being rejected by others because of my hair loss				
16. I have attended support group meetings				
17. I prefer to do things by myself because of my alopecia areata				
18. I have told my friends about my alopecia areata				
19. I have gotten scalp injections for my alopecia areata				
20. I feel that I am a special person because of my alopecia areata				
21. I have a hard time making friends				
22. My family and I have attended a professional conference like the National Alopecia Areata Foundation (NAAF) or Children's Alopecia Project (CAP)				
23. I am okay with the way I look				
24. I enjoy hanging out at the mall with my friends				
25. I have used prescription creams for my hair loss				
26. I am afraid to tell my friends about my alopecia areata				
27. People have made fun of me because I am bald				
28. I wear hairpieces (wigs) all the time				
29. Having alopecia areata makes me angry with myself				
30. I participate in sports with my friends				
31. I tell people about my alopecia areata if they ask				
32. I can do things as well as my				

classmates				
33. I think about my hair loss daily				
34. I have tried different diets (diary, protein, veggie, meatless) to grow my hair back				
35. I feel that I have the same opportunities as other people				
36. I often cry about my hair loss				
37. I have tried different types of shampoos and conditioners for my hair loss				
38. I have accepted my hair loss				
39. I have many good qualities				
40. I have looked up information and resources online about alopecia areata				
41. I have continued to live my life as it was before getting alopecia areata				
42. I would never change the way I look				
43. I use social network sites to talk to friends (Facebook, Twitter, Blogs, YouTube) about alopecia areata				

Part 2: You and Your Family

Directions: For the following questions, please check the appropriate box (one box only)

44. Your current age:

1.	<10	
2.	10	
3.	11	
4.	12	
5.	13	
6.	14	
7.	15	

8.	16	
9.	17	
10.	18	
11.	19	
12.	>19	

45. Your gender:

1.	Male	
2.	Female	

46. Your ethnic background:

1.	Caucasian	
2.	African American	
3.	Asian American	
4.	Hispanic	
5.	Other	

47. Are you a student?

1.	Yes	
2.	No	

48. I have had to change schools because of my alopecia areata

1.	Yes	
2.	No	

49. I have been in special education classes because of my alopecia areata

1.	Yes	
2.	No	

50. Being bullied:

1.	Yes, I have been bullied because of my hair loss	
2.	No, I have not been bullied because of my hair loss	

51. Region I live in:

1.	Northeast: ME, NH, VT, MA, RI, CT, NY, PA, NJ	
----	---	--

2.	Southeast: MD, DE, WV, VA, KY, TN, NC, SC, GA, FL, AL, MS, LA, AR	
3.	Midwest: OH, IN, IL, MI, WI, MN, IA, MO, KS, NE, SD, ND	
4.	Southwest: TX, OK, NM, AZ	
5.	Rocky Mountain: CO, UT, NV, MT, WY, ID	
6.	Pacific: WA, OR, CA	
7.	Noncontiguous (Alaska, Hawaii)	

52. Region location:

1.	Urban (in a large city)	
2.	Suburban (outside of a city)	
3.	Rural (in the country)	

53. My age when I was diagnosed with alopecia areata

1.	<1	
2.	1	
3.	2	
4.	3	
5.	4	
6.	5	
7.	6	
8.	7	
9.	8	
10.	9	
11.	10	
12.	11	
13.	12	
14.	13	
15.	14	
16.	15	
17.	16	
18.	17	
19.	18	
20.	19	
21.	>19	

54. My current alopecia status is:

1.	I was diagnosed with alopecia areata, but my hair has grown back	
2.	I was diagnosed with alopecia areata, and my hair has NOT	

grown back	
------------	--

55. Alopecia areata family history

1. Someone in my immediate family also has alopecia areata (mom, dad, sibling)	
2. Someone in my extended family has alopecia areata (aunt, uncle, cousin)	
3. I do not know of anyone in my family with alopecia areata	

56. I have had alopecia areata for the following number of years:

1.	<1	
2.	1	
3.	2	
4.	3	
5.	4	
6.	5	
7.	6	
8.	7	
9.	8	
10.	9	
11.	10	
12.	11	
13.	12	
14.	13	
15.	14	
16.	15	
17.	16	
18.	17	
19.	18	
20.	19	
21.	>19	

Thank you for participating in this survey.

Would you be willing to participate in a follow-up group interview of approximately 4 to 6 people (30 to 60 minutes) or an individual interview via: Skype or in person (30 to 60 minutes)?

3. Yes

4. No

If Yes, please provide an e-mail address, phone number or both so that I can contact you:

E-mail address: _____

Phone number: _____

All information will be kept strictly confidential. If you feel more comfortable, please contact me via my e-mail address on the cover letter.

Appendix J

E-mail follow-up after 1 week

If you have completed the survey on alopecia areata, thank you. If you are between 10 and 19 years old and have not completed this survey, we would like your view point.

Please click on the link below to begin the 15 minute survey. Thanks for making a difference!

AAsurveylink.tobedetermined.snapsurvey.com

Appendix K

E-mail follow-up after 2 weeks

Thank you, if you have completed the survey on alopecia areata. If you have not, time is running out and we would love to hear from you. Please click on the link below to begin the 15 minute survey. Thank you!

AAsurveylink.tobedetermined.snapsurvey.com

Appendix L

Twitter Cover Letter

Age 10 – 19 with alopecia? Take this survey and help with a study. Thanks

(Survey website – [click here](#))

Appendix M

Interview Guide Individual Interviews

Introduction

Child/Adolescent Questions:

1. Describe your feelings about having and living with AA?
2. What strategies do you use to cope with your AA?
3. How do other people make you feel about AA?
4. How has AA influenced the type of activities you choose to do? Indoor sports vs. outdoor sports (e.g., sports, fine arts, performing arts, recreation, exercise)?
5. What has been the most difficult situation you have had to deal with, with AA? What has been a positive experience you have had?
6. How has your self-perception been impacted by AA? Has there been any change?
7. How has your opinion/experience about having AA changed over time?

Closing: Is there any additional information you would like to share? Do you have any questions for me?

Demographic Information

Participant Pseudonym	Age	M/F	Student Yes/No	Bullied Yes/No	Location	Age of Dx	# Years with AA

Field Notes

Introduction: Explain study and procedure

Child/Adolescent Questions:

1. Describe your feelings about having and living with AA?	
2. What strategies do you use to cope with your AA?	
3. How do other people make you feel about AA	
4. How has AA influenced the type of activities you choose to do? Indoor sports vs. outdoor sports (sports, fine arts, performing arts, recreations, exercise)?	
5. What is the most difficult situation you have had to deal with, with AA? What has been a positive experience you have had?	
6. How has your self-perception been impacted by AA? Has there been any change?	
7. How has your opinion/experience to having AA changed over time?	

REFERENCES

- Al-Mutairi, N., & Eldin, O. N. (2011). Clinical profile and impact on quality of life: Seven years experience with patients of alopecia areata. *Indian Journal of Dermatology, Venerology, and Leprology*, 77, 489-493. doi: 10.4103/0378-6323.82411
- Alkhalifah, A. (2011). Topical and intralesional therapies for alopecia areata. *Dermatologic Therapy*, 24, 355-363.
- Alkhalifah, A. (2013). Alopecia areata update. *Dermatology Clinic*, 31, 93-108.
- American Psychological Association (2002). A reference for professionals, developing adolescents. Maternal and Child Health Bureau. Health Resources and Services Administration. U.S. Department of Health and Human Services. Retrieved from: <http://www.apa.org/pi/families/resources/develop.pdf>
- Anderson, D. M., & Skemp, K. M. (2012). Self-image differences as related to body image of students in a middle school. *American Journal of Health Behavior* 36, 533-541. doi: <http://dx.doi.org/10.5993/AJHB.36.4.10>
- Asbjornslett, M., Engelsrud, G. H., & Helseth, S. (2011). Friendship in all directions: Norwegian children with physical disabilities experiencing friendship. *Childhood* 19, 481-494. doi: 10.1177/0907568211428093
- Avery, P. G., Bird, K., Johnstone, S., Sullivan, J. L., & Thalhammer, K. (1992). Exploring political tolerance with adolescents. *Theory and Research in Social Education* 20, 386-420.
- Baines, A. D., Partin, M. R., Davern, M., & Rockwood T. H. (2007). Mixed-mode administration reduced bias and enhanced poststratification adjustments in a health behavior survey. *Journal of Clinical Epidemiology* 60, 1246-1255. doi: 10.1016/j.jclinepi.2007.02.011
- Bardazzi, F., Neri, I., Raone, B., & Patrizi, A. (1999). Congenital alopecia areata: Another case. *Dermatology*, 198, 199-369.

- Bartrop, R. W., Lazarus, L., Luckhurst, E., Kiloh, L. G., & Penny, R. (1977). Depressed lymphocyte function after bereavement. *Lancet*, *1*, 834-836.
- Basili, V. R. (2013). *Software metrics: An analysis and evaluation*. Chapter 8. Retrieved from <http://www.cs.umd.edu/~basili/publications/chapters/C12.pdf>
- Beard, H. O. (1986). Social and psychological implications of alopecia areata. *Journal of the American Academy of Dermatology*, *14*, 697-700.
- Bedocs, L. A., & Bruckner, A. L. (2008). Adolescent hair loss. *Current Opinion in Pediatrics*, *20*, 431-435.
- Bilgic, O., Bilgic, A., Bahali, K., Bahali, A. G., Gurkan, A., & Yilmaz, S. (2013). Psychiatric symptomatology and health-related quality of life in children and adolescents with alopecia areata. *European Academy of Dermatology and Venereology*, Nov. 16, 1-6. doi: 10.1111/jdv.12315
- Boeije, H. (2002). A purposeful approach to the constant comparative method in the analysis of qualitative interviews. *Quality & Quantity*, *36*, 391-409.
- Borgers, N., de Leeuw, E., & Hox, J. (2000). Children as respondents in survey research: Cognitive development and response quality 1. *Association Internationale de Methodologie Sociologique*, *66*, 60-75. doi: 10.1177/075910630006600106
- Borgers, N., Hox, J., & Sikkels, D. (2004). Response effects in surveys on children and adolescents: The effect of number of response options, negative wording, and neutral mid-point. *Quality & Quantity*, *38*, 17-33.
- Borsellino, M., & Young, M. M. (2011). Anticipatory coping: Taking control of hair loss. *Clinical Journal of Oncology Nursing*, *15*, 311-315. doi: 10.1188/11.CJON.311-315
- Bowman, C. A., & Gordon, P. A. (2000). Izzy, willy-nilly: Issues of disability for adolescents and their families. In C. A. Bowman (ed.), *Using literature to help troubled teenagers cope with health issues* (pp. 27-49). Westport, CT: Greenwood Press.
- Bukatko, D. (2008). *Child and adolescent development: A chronological approach*. Boston, MA: Houghton Mifflin Company.
- Buri, J. R. (1989). Self-esteem and appraisals of parental behavior. *Journal of Adolescent Research*, *4*, 33-49. doi: 10.1177/074355488941003

- Cash, T. F. (1990). Losing hair, losing points?: The effects of male pattern baldness on social impression formation. *Journal of Applied Social Psychology*, 20, 154-167.
- Cash, T. F. (1999). The psychosocial consequences of androgenetic alopecia: A review of the research literature. *British Journal of Dermatology*, 141, 398-405.
- Cash, T. F. (2009). Attitudes, behaviors, and expectations of men seeking medical treatment for male pattern hair loss: Results of a multinational survey. *Current Medical Research and Opinions*, 25, 1811-1820.
- Cash, T. F., Price, V. H., & Savin, R. C. (1993). Psychological effects of androgenetic alopecia on women: Comparisons with balding men and with female control subjects. *Journal of the American Academy of Dermatology*, 29, 568-575.
- Children's Alopecia Project (2012). Retrieved from http://www.childrensalopeciaproject.org/cap/index.php?option=com_frontpage&Itemid=1
- Chu, S-Y, Chen, Y-J, Tseng, W-C, Lin, M-W, Chen, T-J, Hwang, C-Y, Chen, C-C, Lee, D-D, Chang, Y-T, Wang, W-J, & Liu, H-N (2011). Psychiatric comorbidities in patients with alopecia areata in Taiwan: A case-control study. *British Journal of Dermatology*, 166, 525-531. doi: 10.1111/j.1365-2133.2011.10714.x
- Colon, E. A., Popkin, M. K., Callies, A. L., Dessert, N. J., & Hordinsky, M. K. (1991). Lifetime prevalence of psychiatric disorders in patients with alopecia areata. *Comprehensive Psychiatry*, 32, 245-251.
- Compas, B. E., Jaser, S. S., Dunn, M. J., & Rodriguez, E. M. (2012). Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology*, 8, 455-480. doi: 10.1146/annurev-clinpsy-032511-143108
- Comrey, A. L. (1988). Factor-analytic methods of scale development in personality and clinical psychology. *Journal of Consulting and Clinical Psychology*, 56, 754-761.
- Comrey, A. L., & Lee, H. B. (1992). *A first course in factor analysis* (2nd ed.). Hillsdale, NJ: Erlbaum Associates.
- Conley, M. (2011). *Good Morning America*. Alopecia areata patients grateful to Martel for baring her bald head. Retrieved from <http://abcnews.go.com/Health/miss-delawares-kayla-martel-shows-bald-beautiful/story?id=12540584>
- Convio (2013). *Understanding email delivery statistics*. Retrieved from http://help.convio.net/site/PageServer?pagename=Admin_Understanding_Email_Delivery_Statistics

- Creswell, J. W. (2008). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research (3rd ed.)*. Upper Saddle River, NJ: Pearson Education, Inc.
- Cronbach, L. J., & Shavelson, R. J. (2004). My current thoughts on coefficient alpha and successor procedures. *Educational and Psychological Measurement*, 64, 391-418. doi: 10.1177/0013164404266386
- Cronk, B. C. (2012). *How to use SPSS: A step-by-step guide to analysis and interpretation (7th ed.)*. Glendale, CA: Pyrczak Publishing.
- Dawkins, J. L. (1996). Bullying, physical disability and the paediatric patient. *Developmental Medicine and Child Neurology*, 38, 603-612.
- DeVellis, R. F. (2012). *Scale development theory and applications (3rd ed.)*. Los Angeles, CA: Sage Publications, Inc.
- De Weert, J., Temmerman, L., & Kint A. (1984). Alopecia areata: a clinical study. *Dermatologica*, 168, 224-229.
- Diamond, K. E. (2001). Relationships among young children's ideas, emotional understanding, and social contact with classmates with disabilities. *Topics in Early Childhood Special Education*, 21, 104-113. doi: 10.1177/027112140102100204
- Diaz-Atienza, F., & Gurpegui, M. (2011). Environmental stress but not subjective distress in children or adolescents with alopecia areata. *Journal of Psychosomatic Research*, 71, 102-107.
- Dillman, D. A., Smyth, J. D., & Christian, L. M. (2009). *Internet, mail, and mixed-modesurveys: The tailored design method (3rd ed.)*. Hoboken, NJ: John Wiley & Sons, Inc.
- Dimitrov, D. M. (2008). *Quantitative research in education: Intermediate and advanced methods*. Oceanside, NY: Whittier Publications, Inc.
- Dimitrov, D. M. (2012). *Statistical methods for validation of assessment scale data in counseling and related fields*. Alexandria, VA: American Counseling Association.
- Dinh, Q. Q., & Sinclair, R. (2007). Female pattern hair loss: Current treatment concepts. *Clinical Interventions in Aging*, 2, 189-199.

- Dorries, B., & Haller, B. (2001). The news of inclusive education: A narrative analysis. *Disability and Society, 16*, 871-891. doi: 10.1080/09687590120084001
- Draelos, Z. D. (2011). Camouflage technique for alopecia areata: What is a patient to do? *Dermatologic Therapy, 24*, 305-310.
- Driscoll, D. L., Appiah-Yeboah, A., Salib, P., & Rupert, D. J. (2007). Merging qualitative and quantitative data in mixed methods research: How to and why not. *Ecological and Environmental Anthropology, 3*, 19-28.
- Egan, S. K., & Perry, D. G. (1998). Does low self-regard invite victimization? *Developmental Psychology, 34*, 299-309.
- Elkin, T. D., Hilker, K. A., & Drabman, R. S. (2006). Anxiety and psychosocial concerns in alopecia areata: A case study. *Clinical Case Studies, 5*, 103-111. doi: 10.1177/1534650103261208
- Elliott, T. R., Frank, R. G., Corcoran, J., Beardon, L., & Byrd E. K. (1990). Previous personal experience and reactions to depression and physical disability. *Rehabilitation Psychology, 35*, 111-120.
- Favazza, P. C. & Odom, S. L. (1997). Promoting positive attitudes of kindergarten-age children toward people with disabilities. *Exceptional Children, 63*, 405-418.
- Favazza, P. C., Phillipsen, L., & Kukmar, P. (2000). Measuring and promoting acceptance of young children with disabilities. *Exceptional Children, 66*, 491-508.
- Field, A. (2005). *Discovering statistics using SPSS (2nd ed.)*. London, UK: Sage.
- Finner, A. M. (2011). Alopecia areata: Clinical presentation, diagnosis, and unusual cases. *Dermatologic Therapy, 24*, 348-354.
- Fowler, F. J. (2009). *Survey research methods: Applied social research methods series (4th ed.)*. Thousand Oaks, CA: Sage Publications, Inc.
- Freedman, T.G. (1994). Social and cultural dimensions of hair loss in women treated for breast cancer. *Cancer Nursing, 17*, 334-341.
- Gallagher, J. (1997). Chemotherapy-induced hair loss: Impact on women's quality of life. *Quality of Life: A Nursing Challenge, 5*(4), 75-80.

- Gay, L. R., Mills, G. E., & Airasian, P. (2009). *Educational research: Competencies for analysis and applications (9th ed.)*. Upper Saddle River, NJ: Pearson Education, Inc.
- Georgala, S., Befon, A., Maniatopoulou, E., & Georgala, C. (2007). Topical use of minoxidil in children and systemic side effects. *Dermatology*, 214, 101-102. doi: 10.1159/000096924
- 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.
- Gilhar, A., Etzioni, A., & Paus, R. (2012). Alopecia areata. *The New England Journal of Medicine*, 366, 1515-1525.
- Glesne, C. (2006). *Becoming qualitative researchers: An introduction (3rd ed.)*. Boston, MA: Pearson Education, Inc.
- Goddard, A. T. (2011). Hair loss in an adolescent. *Journal of Pediatric Health Care*, 25, 261-265. doi: 10.1016/j.pedhc.2010.12.007
- Godwin, K., Ausbrooks, C., & Martinez, V. (2001). Teaching tolerance in public and private schools. *Phi Delta Kappan* 82, 542-546.
- Green, S. B., & Salkind, N. J. (2011). *Using SPSS for Windows and Macintosh: Analyzing and understanding data (6th ed.)*. Upper Saddle River, NJ: Pearson Education, Inc.
- Grice, K. (2002). Eligibility under IDEA for other health impaired children. *School Law Bulletin*, 33, 7-12.
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology*, 29(2), 75-91.
- Halbesleben, J. R. B., & Whitman, M. V. (2013). Evaluating survey quality in health services research: A decision framework for assessing nonresponse bias. *Health Services Research* 48, 913-930. doi: 10.1111/1475-6773.12002
- Harrison, S., & Sinclair R. (2003). Optimal management of hair loss (alopecia) in children. *American Journal of Clinical Dermatology*, 4, 757-770.
- Hawryluk, E. B., & English, J. C. (2009). Female adolescent hair disorders. *Journal of Pediatric Adolescent Gynecology*, 22, 271-281. doi: 10.1016/j.jpag.2009.03.007

- Heaven, P., & Ciarrochi, J. (2008). Parental styles, gender and the development of hope and self-esteem. *European Journal of Personality*, 22, 707-724. doi: 10.1002/per.699
- Hertzog, M. A. (2008). Considerations in determining sample size for pilot studies. *Research in Nursing & Health*, 31, 180-191. doi: 10.1002/nur.20247
- Hewitt-Taylor, J., (2001). Use of constant comparative analysis in qualitative research. *Nursing Standard*, 15(42), 39-42.
- Hilton, L. (2001). Alopecia areata common in children. *Dermatology Times*, 22, 21-24.
- Hodges, E. V. E., Malone, M. J., & Perry, D. G. (1997). Individual risk and social risk as interacting determinants of victimization in the peer group. *Developmental Psychology*, 33, 1032-1039.
- Hughes, D. J., Rowe, M., Batey, M., & Lee, A. (2012). A tale of two sites: Twitter vs. Facebook and the personality predictors of social media usage. *Computers in Human Behavior*, 28, 561-569.
- Hunt, N., & McHale, S. (2005a). Reported experiences of persons with alopecia areata. *Journal of Loss and Trauma*, 10, 33-50. doi:10.1080/15325020490890633
- Hunt, N., & McHale, S. (2005b). The psychological impact of alopecia. *British Medical Journal*, 331, 951-953.
- Hurst, C., Corning, K., & Ferrante, R. (2012). Children's acceptance of others with disability: The influence of a disability-simulation program. *Journal of Genetic Counselors*, 21, 873-883. doi: 10.1007/s10897-012-9516-8
- Invernizzi, G., Gala, C., Russo, R., Polenghi, M., Manca, G., & Conte, G. (1987). Life events and personality factors in patients with alopecia areata. *Medical Science Research*, 15, 1219-1220.
- Isaac, S., & Michael, W. B. (1982). *Handbook in research and evaluation: For education and the behavioral sciences (2nd ed.)*. San Diego, CA: EdITS Publishers.
- Ito, T. (2011). Advances in the management of alopecia areata. *Journal of Dermatology*, 39, 11-17. doi: 10.1111/j.1346-8138.2011.01476.x

- Kakourou, T., Karachristou, K., & Chrousos, G. (2007). A case series of alopecia areata in children: Impact of personal and family history of stress and autoimmunity. *Journal of the European Academy of Dermatology and Venereology*, 21, 356-359. doi: 10.1111/j.1468-3083.2006.01931.x
- Kalabokes, V. D. (2011). Alopecia areata: Support groups and meetings – how can it help your patient? *Dermatologic Therapy*, 24, 302-304.
- Keeping Kids Safe Online (2013). *Scholastic.com*. Retrieved from <http://www.scholastic.com/parents/resources/article/>
- Kos, L., & Conlon, J. (2009). An update on alopecia areata. *Current Opinion in Pediatrics*, 21, 475-480. doi: 10.1097/MOP.0b013e32832db986
- Kose, O., Sayar, K., & Ebrinc, S. (2000). Psychometric assessment of alopecia areata patients before and after dermatological treatment. *Bulletin of Clinical Psychopharmacology*, 10, 21-25.
- Koszalinski, R. S., & Williams, C. (2012). Embodying identity in chemotherapy-induced alopecia. *Perspectives in Psychiatric Care*, 48, 116-121. doi: 10.1111/j.1744-6163.2011.00314.x
- Kranz, D. (2011). Young men's coping with androgenetic alopecia: Acceptance counts when hair gets thinner. *Body Image*, 8, 343-348. doi: 10.1016/j.bodyim.2011.06.006
- Krejcie, R. V., & Morgan, D. W. (1970). Determining sample size for research activities. *Educational and Psychological Measurement*, 30, 607-610.
- Kreuter, F. (2013). Facing the nonresponse challenge. *The Annals of the American Academy of Political and Social Science*, 645, 23-35. doi: 10.1177/0002716212456815
- Kyser, E. A. (1993). *Coping styles and adjustment factors of alopecia areata* (Doctoral dissertation). The California School of Professional Psychology, Berkeley/Alameda, CA.
- Lawshe, C. H. (1975). A quantitative approach to content validity. *Personnel Psychology*, 28, 563-575.
- Lee, S., Yoo, S., & Bak, S. (2003). Characteristics of friendships between children with and without mild disabilities. *Education and Training in Developmental Disabilities*, 38, 157-166.

- Liakopoulou, M., Alifieraki, T., Katideniou, A., Kakourou, T., Tselalidou, E., Tsiantis, J., & Stratigos, J. (1997). Children with alopecia areata: Psychiatric symptomatology and life events. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36, 678-684.
- Llewellyn, A. (2000). Perceptions of mainstreaming: A systems approach. *Developmental Medicine & Child Neurology*, 42, 106-115.
- Lohtia, R., Donthu, N., & Hershberger, E. K. (2004). The impact of content and design elements on banner advertising click-through rates. *Journal of Advertising Research*, 43, 410-418. doi: 10.1017/S0021849903030459
- Lu, W., Shapiro, J., Yu, M., Barekatin, A., Lo, B., Finner, A., & McElwee, K. (2006). Alopecia areata: Pathogenesis and potential for therapy. *Expert Reviews in Molecular Medicine*, 8(14), 1-12. doi: 10.1017/S146239940601101X
- MacDonald, N. (1999). Alopecia areata: Identification and current treatment approaches. *Dermatology Nursing*, 11, 356-364.
- MacDonald Hull, S. P., Wood, M. L., Hutchinson, P. E., Sladden, M., & Messenger, A. G. (2003). Guidelines for the management of alopecia areata. *British Journal of Dermatology*, 149, 692-699.
- MacLean, K. J., & Tidman, M. J. (2013). Alopecia areata: more than skin deep. *The Practitioner*, 257, 29-32.
- Madani, S., & Shapiro J. (2000). Alopecia areata update. *Journal of the American Academy of Dermatology*, 42, 549-566. doi: 10.1067/mjd.2000.103909
- Manchester, P. B. (1981). The adolescent with cancer: Concerns for care. *Topics in Clinical Nursing*, 2, 31-37.
- Massey, D. S., & Tourangeau, R. (2013). Where do we go from here? Nonresponse and social measurement. *The Annals of the American Academy of Political and Social Science*, 645, 222-236. doi: 10.1177/0002716212463191
- 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
- Maxwell, J. A. (2005). *Qualitative research design: An interactive approach (2nd ed.)*. Thousand Oaks, CA: Sage Publications, Inc.

- McKillop, J. (2010). Management of autoimmune associated alopecia areata. *Nursing Standard, 24*, 42-46.
- Mertler, C. A., & Vannatta, R. A. (2002). *Advanced and multivariate statistical methods: Practical application and interpretation (2nd ed.)*. Los Angeles, CA: Pyrczak Publishing.
- Messenger, A. G., McKillop, J., Farrant, P., McDonagh, A. J., & Sladden, M. (2012). British association of dermatologists' guidelines for the management of alopecia areata 2012. *British Journal of Dermatology, 166*, 916-926. doi: 10.1111/j.1365-2133.2012.10955.x
- Monselise, A., Bar-On, R., Chan, L., Leibushor, N., McElwee, K., & Shapiro, J. (2013). Examining the relationship between alopecia areata, androgenetic alopecia, and emotional intelligence. *Journal of Cutaneous Medicine and Surgery, 17*, 46-51. doi: 10.2310/7750.2012.12003
- Mounsey, A. L., & Reed, S. W. (2009). Diagnosing and treating hair loss. *American Family Physician, 80*, 356-362.
- Mukherjee, N., Burkhart, C. N., & Morrell, D. S. (2009). Treatment of alopecia areata in children. *Pediatric Annals, 38*, 388-395. doi: 10.3928/00904481-20090511-07
- Munstedt, K., Manthey, N., Sachsse, S., & Vahrson, H. (1997). Changes in self-concept and body image during alopecia induced cancer chemotherapy. *Support Care Cancer, 5*, 39-143.
- Nanda, A., Al-Fouzan, A. S., & Al-Hasawi, F. (2002). Alopecia areata in children: A clinical profile. *Pediatric Dermatology, 19*, 482-485.
- National Alopecia Areata Foundation (n. d.). *"Education on the move": A project promoting Alopecia Areata in the elementary school classroom*. [Handbook]. San Rafael, CA: Author
- National Alopecia Areata Foundation (2011a). *Alopecia areata: A parent's guide*. [Brochure]. San Rafael, CA: Author
- National Alopecia Areata Foundation (2011b). *Alopecia areata: From a child's point-of-view*. [Brochure]. San Rafael, CA: Author
- National Alopecia Areata Foundation (2011c). *Alopecia areata: Helping you cope with alopecia areata*. [Brochure]. San Rafael, CA: Author

- National Alopecia Areata Foundation (2011d). *Alopecia areata: What you should know*. [Brochure]. San Rafael, CA: Author
- Nield, L. S., Keri, J. E., & Kamat, D. (2006). Alopecia in the general pediatric clinic: Who to treat, who to refer. *Clinical Pediatrics*, 45, 605-612. doi:10.1177/0009922806291011
- Nulty, D. D. (2008). The adequacy of response rates to online and paper surveys: What can be done? *Assessment & Evaluation in Higher Education*, 33, 301-314. doi: 10.1080/02602930701293231
- Olney-Friedrich, M. (November/December 2001). Empathy: Recognizing a teachable moment. Retrieved from www.TeachingK-8.com
- Osman, O. T., Mufaddel, A., Almugaddam, F., & Augusterfer, E. F. (2011). The psychiatric aspects of skins disorders. *Expert Reviews on Dermatology*, 6, 195-209.
- Owens, K. B. (2002). *Child & adolescent development: An integrated approach*. Belmont, CA: Wadsworth/Thomson Learning.
- Paga, G., Faina, P., Teodori, A., Angelini, E., Biondi, M., Ruvinetti, S., & Pancheri, P. (1992). Psychological factors in alopecia areata: Results from a preliminary, controlled study. *New Trends in Experimental and Clinical Psychiatry*, 8, 73-79.
- Papadopoulos, A. J., Schwartz, R. A., & Janniger, C. K. (2000). Alopecia areata: Pathogenesis, diagnosis, and therapy. *American Journal of Clinical Dermatology*, 1, 101-105.
- Patten, M. L. (2011). *Questionnaire research: A practical guide (2nd ed.)*. Los Angeles, CA: Pyrczak Publishing.
- Pennington, L. (1993). *Alopecia areata: Age and gender differences in self-esteem, depression and stress* (Doctoral dissertation). California School of Professional Psychology, Los Angeles, CA.
- Perini, G. I., Fornasa, C. V., Cipriani, R., Bettin, A., Zecchino, F., & Peserico, A. (1984). Life events and alopecia areata. *Psychotherapy and psychosomatics*, 41, 48-52.
- Picardi, A., & Abeni, D. (2001). Stressful life events and skin diseases: Disentangling evidence from myth. *Psychotherapy and Psychosomatics*, 70, 118-136.
- Price, V. H., & Khoury, E. L. (1991). Alopecia areata. *Progress in Dermatology*, 25, 1-7.

- Prickitt, J., McMichael, A. J., Gallagher, L., Kalabokes, V., & Boeck, C. (2004). Helping patients cope with chronic alopecia areata. *Dermatology Nursing, 16*, 237-241.
- Putt, S. C., Weinstein, L., & Dzindolet M. T. (1994). A case study: Massage, relaxation, and reward for treatment of alopecia areata. *Psychological Reports, 74*, 1315-1318.
- Raquepaw, J. M. (1990). *Psychological and behavioral effects of alopecia* (Doctoral dissertation). Texas A & M University.
- Reeve, E. A., Savage, T. A., & Bernstein G. A. (1996). Psychiatric diagnoses in children with alopecia areata. *Journal of the American Academy on Child and Adolescent Psychiatry, 35*, 1518-1522.
- Roberts, C. M., & Lindsell, J. S. (1997). Children's attitudes and behavioral intentions towards peers with disabilities. *International Journal of Disability Development, 44*, 133-145.
- Rumsey, N., & Harcourt, D. (2004). Body image and disfigurement: Issues and interventions. *Body Image, 1*, 83-97. doi: 10.1016/S1740-1445(03)00005-6
- Safavi, K. H., Muller, S. A., Suman, V. J., Moshell, A. N., & Melton, J. L. (1995). Incidence of alopecia areata in Olmsted County, Minnesota, 1975 through 1989. *Mayo Clinical Proceedings, 70*, 628-633.
- Sawyer, M. G., Borojevic, N., Ettridge, K. A., Spence, S. H., Sheffield, J., & Lunch, J. (2012). Do help-seeking intentions during early adolescence vary for adolescents experiencing different levels of depressive symptoms? *Journal of Adolescent Health, 50*, 236-242.
- Shenefelt, P. D. (2003). Applying hypnosis in dermatology. *Dermatology Nursing, 15*, 513-538.
- Silverberg, N. B. (2006). Helping children cope with hair loss. *Cutis, 78*, 333-336.
- Simon, M. K. (2011). *Dissertation and scholarly research: Recipes for success*. Seattle, WA: Dissertation Success, LLC.
- Sinclair, R., Patel, M., Dawson, T. L., Yazdabadi, A., Yip, L., Perez, A., & Rufaut, N. W. (2011). Hair loss in women: Medical and cosmetic approaches to increase scalp hair fullness. *British Association of Dermatologists, 165*, 12-18. doi: 10.1111/j.1365-2133.2011.10630x

- Smith, J. A. (2001). The impact of skin disease on the quality of life of adolescents. *Adolescent Medicine: State of the Art Reviews*, 12, 343-353.
- Snap Surveys (2012). Retrieved from <http://www.snapsurveys.com/software/us/>
- Spano, S. (2004). *Stages of adolescent development: ACT for youth upstate center of excellence research facts and findings*. Cornell University Family Life Development Center. Retrieved from http://www.actforyouth.net/resources/rf/rf_stages_0504.pdf
- Springhouse Nurse's Drug Guide* (2004, 5th ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- Stopbullying.gov (2014). *Working in the community*. U.S. Department of Health and Human Services. Retrieved from: <http://www.stopbullying.gov/prevention/in-the-community/index.html>
- Subrahmanyam, K., Reich, S. M., Waechter, N., & Espinoza, G. (2008). Online and offline social networks: Use of social networking sites by emerging adults. *Journal of Applied Developmental Psychology* 29, 420-433. doi: 10.1016/j.appdev.2008.07.003
- Taber's Cyclopedic Medical Dictionary (22nd ed.). 2013. Philadelphia, PA: F. A. Davis Company.
- Tan, E., Tay, Y. K., Goh, C. L., & Giam, Y. C. (2002). The pattern and profile of alopecia areata in Singapore – a study of 219 Asians. *International Journal of Dermatology*, 41, 748-753.
- Tan, E., Tay, Y., & Giam, Y. (2002). A clinical study of childhood alopecia areata in Singapore. *Pediatric Dermatology*, 19, 298-301.
- Tavakol, M., & Dennick, R. (2011). Making sense of Cronbach's alpha. *International Journal of Medical Education*, 2, 53-55. doi: 10.5116/ijme.4dfb.8dfd
- Tagxedo (2013). Retrieved from <http://www.tagxedo.com/app.html>
- Tecoma, E. S., & Huey, L. Y. (1985). Psychic distress and the immune response. *Life Sciences*, 36, 1799-1812.
- Tenenbaum, H. R., & Leaper, C. (2003). Parent-child conversations about science: The socialization of gender inequities? *Developmental Psychology*, 39, 34-47.

- The Pew Research Center for the People & The Press (2007). *How young people view their lives, futures and politics: A portrait of "generation next."* A survey conducted in association with: The generation next initiative and documentary produced by MacNeil/Lehrer Productions. Retrieved from <http://www.people-press.org/2007/01/09/a-portrait-of-generation-next/>
- Thomas, E. A., & Kadyan, R. S. (2008). Alopecia areata and autoimmunity: A clinical study. *Indian Journal of Dermatology*, 53, 70-74.
- Tinsley, H. E. A., & Tinsley, D. J. (1987). Uses of factor analysis in counseling psychology research. *Journal of Counseling Psychology*, 34, 414-424.
- Tosti, A., & Gray, J. (2007). Assessment of hair and scalp disorders. *Journal of Investigative Dermatology Symposium Proceedings*, 12, 23-27. doi: 10.1038/sj.jidsymp.5650051
- Tucker, P. (2009). Bald is beautiful? The psychosocial impact of alopecia areata. *Journal of Health Psychology*, 14, 142-150. doi: 10.1177/1359105308097954
- Twyman, K. A., Saylor, C. F., Saja, D., Macias, M. M., Taylor, L. A., & Spratt, E. (2010). Bullying and ostracism experiences in children with special health care needs. *Journal of Developmental and Behavioral Pediatrics*, 31, 1-8.
- U.S. Department of Commerce, U.S. Census Bureau (2012). Retrieved from <http://quickfacts.census.gov/qfd/states/00000.html>
- Valkenburg, P. M., & Peter, J. (2007). Preadolescents' and adolescents' online communication and their closeness to friends. *Developmental Psychology*, 43, 267-277. doi: 10.1089/cpb.2006.9.584
- Vandegrift, K. V. (1994). The development of an oncology alopecia wig program. *Journal of Intravenous Nursing*, 17, 78-82.
- Van der Donk, J., Hunfeld, J. A. M., Passchier, J., Knegt-Junk, K. J., & Nieboer, C. (1994). Quality of life and maladjustment associated with hair loss in women with alopecia androgenetica. *Social Science and Medicine*, 38, 159-163.
- Villanueva, C. (2012). In *CBS News Sports*. Retrieved from http://www.cbsnews.com/8301-31751_162-20021692-10391697.html
- Weigel, M. (2012). Overview of state anti-bullying legislation and other related laws. *Journalist's Resource: Research on Today's News Topics*. Retrieved from <http://journalistsresource.org/studies/society/education/federal-state-anti-bullying-legislation-laws/#>

- Welsh, N., & Guy, A. (2009). The lived experience of alopecia areata: A qualitative study. *Body Image*, 6, 194-200. doi:10.1016/j.bodyim.2009.03.004
- Willemsen R., & Vanderlinden, J. (2008). Hypnotic approaches for alopecia areata. *International Journal of Clinical and Experimental Hypnosis*, 56, 318-333.
- Willemsen, R., Vanderlinden, J., Deconinck, A., & Roseeuw, D. (2006). Hypnotherapeutic management of alopecia areata. *Journal of the American Academy of Dermatology*, 55, 233-237. doi: 10.1016/j.jaad.2005.09.025
- Wodrich, D. L., & Spencer, M. L. S. (2007). The other health impairment category and health-based classroom accommodations: School psychologists' perceptions and practices. *Journal of Applied School Psychology*, 24, 109-125. doi:10.1300/J370v24n01_06
- Yell, M. L. (2006). *The law and special education (2nd ed.)*. Upper Saddle River, NJ: Pearson Education, Inc.

BIOGRAPHY

Janice J. Wolf graduated from Bay Village High School, Bay Village, Ohio in 1972. She received her Bachelor's in Business Education from Bowling Green State University, Bowling Green, Ohio in 1976. She also received her Bachelor's in Nursing from George Mason University, Fairfax, VA in 1984. While working as a teacher in Fairfax County, she received her Master's in Education (Special Education) from George Mason University in 2007.