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

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Alopecia Areata (AA)

■ Alopecia Areata:

- Chronic, spontaneous disorder characterised by partial or total hair loss with no scarring or permanent damage to the affected area¹
- The area retains the potential for hair regrowth and subsequent relapse.
- The scalp is the most commonly affected area, but any hair bearing site on the body can be affected²
- Approximately 2% of the global population have some form of AA²
- There is no cure³

Types of Alopecia Areata

- Alopecia Areata Monolocularis⁴
 - A singular or isolated area of hair loss, occurring on any part of the scalp;
- Alopecia Areata Multilocularis
 - Multiple patches of hair loss that may merge together forming larger areas of hair loss
- Alopecia Areata Totalis
 - Severe form which causes complete loss of scalp hair
- Alopecia Areata Universalis
 - Complete loss of scalp and body hair

Images of Alopecia Areata

Alopecia Areata Monolocularis



Photos' Courtesy of the AAAF Inc.

Alopecia Areata Multilocularis



Images of Alopecia Areata

Alopecia Areata Totalis

Alopecia Areata Universalis



Photos' Courtesy of the AAAF Inc.



Aetiology

- Hypothesized to be an organ specific Autoimmune disorder⁵
- Possible causes have been identified in individuals with AA:
 - Genetic predisposition⁵
 - Emotional and physical traumatic events⁶
 - Psychological stress^{7,8}

Depression & Anxiety

 Several studies demonstrate high prevalence of psychological distress among people with AA

- Individuals may be at a higher risk of developing depression, anxiety or other disorders⁹
- There are studies which have not confirmed any association between AA and Depression & Anxiety¹⁰

Quality of Life

- AA has been linked to some negative psychosocial consequences¹¹:
 - Emotional pain and suffering
 - Negative effects on daily functioning and lifestyle

- Negative physical aspects:
 - Physical aspects
 - Symptoms

Coping

- Some literature has focused on coping with AA¹¹
 - Practically
 - Psychologically
 - Socially

 Verification of specific, beneficial coping strategies for young individuals with AA is limited

Aim

The aim of the research was to investigate Coping, Quality of Life, Depression & Anxiety in Adolescents & Young Adults with Alopecia Areata

Rationale

- Provide information to the Australia Alopecia Areata Foundation Inc. (AAAF) and to assist those diagnosed with the condition.
- □ To encourage research concerning the condition Alopecia Areata.

Methodology

Questionnaires:

- Demographic Questions
- DASS42
- Skindex29
- Brief COPE

Sample:

- Males and Females
 - 12 to 25 Years
 - Diagnosis of AA

Analysis:

- t-tests (single sample)
- Correlation
- Theme identification

Recruitment Time:

• 1 $\frac{1}{2}$ Months

Results:

Psychological States: Anxiety Depression & Stress

Psychological States: Anxiety, Depression & Stress

- No significantly elevated Anxiety, Depression or Stress levels
 - In comparison to normative data from an Australian sample aged 18-24 and an Adult sample from the UK
 - The majority of this AA sample fell in the normal category.
 - The majority appear to be coping well with the condition.

Anxiety, Depression & Stress: Mean Results for the DASS42

Australian Normative Data		UK Normative Data	
Depression	7.75	Depression	5.55
Anxiety	5.34	Anxiety	3.56
Stress	10.04	Stress	9.27
	AA Sample Data		
	Depression	9.26	
	Anxiety	6.23	
	Stress	10.86	

^{**}Note: Depression and Anxiety were not elevated in this group

Results:

Quality of Life & Concerns about Alopecia Areata

Quality of Life: Short Answer Responses

- The short answer responses presented some concerns:
 - Reactions from the public (people starring or assuming they have cancer). This is due to lack of knowledge and awareness about the condition.
 - Emotional aspects were mentioned such as worrying about the condition.
 - There was an impact on daily functioning and activities (for instance, going to the beach or swimming).

Concerns about Alopecia Areata

Concerns about living with AA	no. (%)
Public Reactions: (e.g. Stares, Laughter, etc.)	23 (59%)
Emotional Aspects (e.g. Worry, Anxiety, etc.)	21 (54%)
Impact on Daily Functioning (e.g. Sports, Activities, etc.)	12 (31%)
Symptoms and Relapse	11 (28%)
Wearing Headpieces (e.g. Wigs, Hats, etc.)	9 (23%)
Disclosure	5 (13%)
Bullying and Loss of Friendships	4 (10%)
Lack of Awareness and Understanding	3 (8%)
Maintenance and Time Consuming	3 (8%)
Concealment	2 (5%)

^{**}Note: Participant responses may be indicative of more than one category

Quality of Life: Skindex29

- Two domains of Quality of Life, Emotions and Functioning, was associated with the Depression and Anxiety domains.
- This suggested:
 - Higher levels of Depression and Anxiety were related to a higher impact the condition had on the emotional state
 - Higher levels of Depression and Anxiety were related to higher levels of impaired daily functioning

^{**}Note: Depression and Anxiety were not elevated in this group

Results:

Coping with Alopecia Areata

Coping: Brief COPE

- The coping mechanisms identified were mainly positive
- Coping skills identified have been beneficial to this group and they appear to be coping well
- Responses from the Brief COPE indicated high use of:
 - Acceptance
 - Active Coping
 - Emotional Support
 - Positive Reframing

Coping Responses

Coping Styles Identified in an AA Sample	no. (%)
Acceptance	12 (40%)
Headwear (e.g. Hats, Beanies, Bandannas, etc)	11 (37%)
Educating and Informing Others	9 (30%)
Support (e.g. AAAF, Family, Friends, etc.)	9 (30%)
Aesthetic (e.g. Wigs, Make-Up, etc.)	8 (27%)
Positive Reframing	3 (10%)
Denial	2 (6%)
Relaxation & Natural Remedies	2 (6%)
Withdrawal	2 (6%)
Self-Distraction	1 (3%)
Sport	1 (3%)

^{**}Note: Participant responses may be indicative of more than one category

Coping Recommendations

- Acceptance & Respect
- Confidence is Key
- Educate & Inform (Yourself & Others)
- Seek Support
 - AAAF
 - Websites such as alopeciaworld.com
 - Family, Friends & Peers
 - Youth ambassadors

Coping Recommendations

- Group Sessions (Sharing Experiences)
- Therapy
- Relaxation
- Exercise
- Active Coping

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