

Alopecia Areata

Exploring the Literature

Sarah R. Caro

OBJECTIVE: The purpose of this search was to review the literature on the subject of alopecia areata.

METHODS: This literary review utilized the library databases of Cumulative Index of Nursing and Allied Health Literature and PubMed as well as the medical research platform Ovid, exploring topics associated with the subject matter of alopecia areata examining issues associated with the autoimmune disorder including diagnosis, treatment, and the patient experience. This investigation examines the diagnosis and progression of the autoimmune disease including relevant and recent literature reflecting research outcomes from the specialties of dermatology, psychology, genetics, and nursing.

RESULTS: In summary, the outcome of the literature exploration reflects research from the specialties of dermatology, psychology, and medicine, revealing numerous difficulties patients diagnosed with alopecia areata experience.

CONCLUSION: The nursing profession pursues research to promote best practice and improve patient outcomes; however, nursing research falls short on the topic of alopecia areata. This autoimmune disorder causes a significant psychological impact on people living with the disease; therefore, individuals diagnosed with the condition experience the unique phenomenon of living without hair. The literature review indicates the need for further investigation of the essence of living with the daily reality of cyclic patterns of hair loss and the resulting health-illness transition from one stable state of health to another state of health.

Key words: Alopecia Areata, Autoimmune Disorder, Diagnosis and Treatment of Alopecia Areata, Treatment, Patient Experience With Medical Services and Healthcare Delivery

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REVIEW OF THE LITERATURE

The autoimmune disorder alopecia areata results in the life-altering effects of living without the defining characteristics of hair. This literary review investigates the literature about the subject matter of alopecia areata by utilizing the Cumulative Index of Nursing and Allied Health Literature, PubMed, and the medical research platform Ovid. The investigation explored topics associated with alopecia areata, including diagnosis, progression, treatment, and the patient experience, and includes research outcomes from the specialties of dermatology, psychology, genetics, and nursing.

Alopecia areata describes a form of hair loss that is unpredictable and incurable and affects 6.8 million people in the United States and 147 million people worldwide (National Alopecia Areata Foundation, 2021). Hair is a defining characteristic of humans and offers protection from the elements. Patients diagnosed with this disorder experience a profound sense of loss, frequently experiencing minimal psychological support (Hunt & McHale, 2005; Münstedt et al., 1997). Human existence without hair often presents an uncertain, unique, and emotionally painful experience for patients.

Medical explanations for hair loss vary with the diagnosis indicating temporary or permanent alopecia; however, the unpredictable nature of this autoimmune disorder limits effective treatment options (Hunt & McHale, 2005). Healthcare providers and cosmetic professionals offer ineffective treatment options for those desperately seeking reversal of the impact of the disease. The treatment goal to restore the appearance of health through hair regrowth usually results in major disappointment (Hunt & McHale, 2005).

The organization of this review provides information about alopecia areata with topics including (a) autoimmune disorder, (b) loss, (c) hopelessness, (d) coping, (e) self-concept, (f) quality of life (QoL), and (g) psychological support.

OVERVIEW OF ALOPECIA AREATA

Autoimmune Disorder

Historically, there have been reports that medical experts considered alopecia areata a psychosomatic disorder initiated by stress response; however, today, the medical community affirms alopecia areata is an autoimmune disease

(Dubois et al., 2010; Hunt & McHale, 2005; Liu et al., 2016; Prickitt et al., 2004). The cyclic pattern of hair loss reflects the diagnosis of a T-cell-mediated disorder lacking a predictable cause and cure (Hunt & McHale, 2005; Prickitt et al., 2004). The diagnosis is confirmed after observing patterns of patchy hair loss followed by the rapid progression of hair loss (Gilhar et al., 2012; Hunt & McHale, 2005). Practitioners find it easy to diagnose this disorder; however, effective treatment is not available (Gilhar et al., 2012). Individuals diagnosed with alopecia areata do not consistently respond to medical treatments or therapeutic interventions with hair growth, and if the person responds to treatment, they may only experience temporary results (Hunt & McHale, 2005).

The multifaceted cause of this disease includes the immune response attacking hair growth in the hair follicles, and a genetic predisposition to the disease includes a family history of Type 1 diabetes, rheumatoid arthritis, asthma, thyroid disease, and atopic eczema (Liu et al., 2016). The first symptoms of alopecia areata often appeared nondescript with small patches of hair loss that may be attributed to other conditions before confirming the diagnosis (Willemse et al., 2019). The medical community often considers the disease benign, but the emotional and psychological impact of alopecia areata is often devastating (Liu et al., 2016). Dubois et al. (2010) also refer to the disease as benign, but the authors acknowledge the importance of sensitive provider care and supportive services. De Hollanda et al. (2014) report comorbidities possibly associated with this autoimmune disorder include vitiligo, lupus erythematosus, psoriasis, atopic dermatitis, thyroid disease, and allergic rhinitis; however, the authors refer to the patients' state of general health as uncompromised.

Research indicates causative and curative measures but does not reflect the benefit of specific psychological support. Willemsen et al. (2008) evaluated the link between childhood trauma and the occurrence of alopecia areata by exploring the relation of short-term stress within a 6- to 12-month timeframe, and the results indicated a higher incidence of the experience of childhood trauma in individuals with alopecia areata than with those in the control group. Genome testing and research define the genetic component of alopecia areata with other autoimmune diseases that initiate the autoimmune response (Petukhova et al., 2010). Alopecia areata requires patients and their loved ones to cope with an incurable, chronic disease.

Coping

Coping is considered an adaptation utilized during occurrences or times of challenging experiences as noted by Gol and Cook's (2004) reference to Costa et al.'s (1996) definition of coping as a "special category of adaptation elicited in normal individuals by unusually taxing circumstances (45)." Physical and psychological health requires coping during times of illness or stress, and varying degrees of

self-concept influence effective coping strategies (Gol & Cook, 2004; Sung, 2011). The pursuit of unreliable treatment for hair regrowth often delays coping (Gilhar et al., 2012; Hunt & McHale, 2005). The emotional turmoil and sense of loss caused by alopecia areata is an event requiring coping strategies to facilitate optimal health.

Patients, family members, and loved ones of people with alopecia areata often report experiencing emotional trauma as a consequence of the psychological impact of the condition (Hunt & McHale, 2005). Minimizing the impact of hair loss fails to facilitate coping, and providers generally display insensitivity with treatment (Hunt & McHale, 2005; Liu et al., 2016).

A study by Welsh and Guy (2009) reported that uncertainty with the episodes of hair loss and treatment contributes to difficulty coping. The literature reveals various studies exploring the QoL for those diagnosed with alopecia areata. Welsh and Guy found the limited treatment options and the episodic progression of the disorder influence coping. Women experience increased distress in comparison with men, and coping strategies differ for men and women (Welsh & Guy, 2009). This study supports the unique phenomenon of living with alopecia areata for both genders; however, participants were experiencing different stages of diagnosis with alopecia areata or alopecia universalis (Welsh & Guy, 2009). This interpretive, phenomenological study explored the lived experience of alopecia areata with a sample size of 12 participants who provided adequate data saturation for differentiation of the lived experiences of stages of alopecia areata and alopecia universalis (Welsh & Guy, 2009). Welsh and Guy acknowledged the benefit of future research for a comparison of the experience of men and women as well as consistency from the time of diagnosis and severity of hair loss, the variables of gender, and experience with the disease may influence the research outcomes. Sensitive provision of care allows patients to describe the experience of loss and cope with the condition without minimizing the result of hair loss.

Current literature indicates urgency in the pursuit of treatment options, but efforts fall short for the development of coping strategies for this patient population. The quest for ineffective treatment generally inhibits coping, and the limited treatment options increase the sense of loss and hopelessness (Hunt & McHale, 2005; Liu et al., 2016; Mirmirani, 2007). Hair embodies the symbol of beauty and health, but therapeutic interventions fail to halt the progression of alopecia areata (Liu et al., 2016; Mirmirani, 2007). The delivery of responsive provider services remains elusive for patients with this condition, and recorded instances reveal that healthcare providers may force individuals to face the reality of hair loss without adequate support (Hunt & McHale, 2005; Mirmirani, 2007). Initial counseling should avoid the use of the term *bald* and should refer to the patient as experiencing hair loss (Mirmirani, 2007).

Matzer et al. (2011) recognized the significant emotional distress caused by alopecia areata leading to their

investigation of the role of coping for patients with the condition. The mixed-methods study included 45 participants with 10 men and 35 women to evaluate coping responses to stress through semistructured interviews, a stress and coping process questionnaire, and the Frankfurt Body Concept Scales. According to Matzer et al., patients with alopecia areata experience extreme emotional distress related to the consequences of the disease, causing changes in body image, an acute fixation on areas of hair loss, and judgments because of changes to their physical appearance. Matzer et al. report that patients with a healthy approach to coping have a positive body image while recognizing the value of a positive body image on coping. The literature supports the benefit of healthy coping strategies, but organized coping resources are often not provided to patients. The value of a strong self-concept is related to concrete coping methods.

Self-Concept

Self-concept refers to an individual's opinion of self, either positive or negative, and self-esteem embodies a component of self-concept (Blatný et al., 2006). Self-concept develops during the life of an individual; therefore, the description changes for each person (Sung, 2011). The presence of hair generally defines personal appearance and represents health. Research reveals common findings that indicate the negative impact alopecia areata has on low self-concept (Hunt & McHale, 2005). The loss of hair remains a devastating reality for people diagnosed with alopecia areata; furthermore, the diagnosis compromises the patient's self-perception, self-esteem, and relationships (Dubois et al., 2010; Hunt & McHale, 2005). Psychological support promotes healthy self-esteem, and the level of self-concept reflects the degree and effectiveness of coping strategies (Fabbrocini et al., 2013; Sung, 2011).

Li et al. (2019) conducted a survey that evaluated the impact of alopecia areata on sexual QoL. The authors utilized a convenience sample of 81 subjects who were recruited through the National Alopecia Areata Foundation (Li et al., 2019). The participants completed the Sexual Quality of Life for Males and the Sexual Quality of Life for Females that evaluate the social, emotional, and psychological components of sexual health (Li et al., 2019). Li et al. reported a convenience sample that included 64 women and 17 men was recruited via the National Alopecia Areata Foundation's patient database. The Sexual Quality of Life for Females and Sexual Quality of Life for Males tools include self-response areas on the topics of sexual activity, guilt, loss, depression, confidence, anger, embarrassment, and anxiety (Li et al., 2019). The results revealed that 75% of women responded to "I feel embarrassed"; 64.1%, to "I feel like less of a woman"; and 64.1%, to "I lost confidence in myself as a sexual partner" (Li et al., 2019).

Loss

Patients diagnosed with alopecia areata often experience a significant sense of loss. Robinson and McKenna (1998)

described loss as follows: (a) an indication of the absences of what one has possessed or should expect to own in the future, (b) the object or subject of the absence reflected value for the one experiencing loss, and (c) the individual experiencing loss provides the subjective description and the context of the loss. Patients experience a change in appearance, confidence, and identity (Welsh & Guy, 2009). The sense of loss results from the absence of hair; the immense value placed on hair as a defining, human characteristic; and the degree of loss as it relates to the individual's subjective report (Münstedt et al., 1997; Robinson & McKenna, 1998; Welsh & Guy, 2009).

Münstedt et al. (1997) investigated the experience of chemotherapy-induced hair loss on a sample of 29 patients with gynecological cancer. The participant inclusion criteria included women less than 75 years old without prior experience of chemotherapy-induced hair loss (Münstedt et al., 1997). The authors used the Frankfurt Body Concept Scale and the Frankfurt Self-Concept Scale to evaluate the participants' body image and self-concept (Münstedt et al., 1997). This investigation showed the significance of the impact of hair loss on self-esteem; furthermore, the authors revealed that the postchemotherapy return of hair growth failed to return self-concept to levels experienced before the hair loss (Münstedt et al., 1997).

Prickitt et al. (2004) report the results of interviewing five dermatology nurses who recognize the impact of hair loss on individuals with alopecia areata that illustrated the benefit of therapeutic nursing interventions and patient support group participation for this patient population. Welsh and Guy (2009) reported the loss of hair drastically changes the facial appearance affecting the impact of the condition. Bhargava et al. (2015) report the significance of the psychological impact of alopecia areata and the importance of psychological support to assist with the perception of disfigurement, grief, and loss. Patients living with this disease often report a lack of hope that a reliable treatment or a cure exists to mend their chronic condition.

Hopelessness

Hopelessness is a negative expectation about oneself and the future, and despair results as a person surrenders attempts to correct or change the situation (Aubin et al., 2016; Beck et al., 1974; Stotland, 1969). The progressive effects of despair contributing to hopelessness result from the following: (a) the impassable reality of the negative situation, (b) the stressor causing the negative situation remains constant over time, (c) the causative negative factor affects others as well, and (d) the uncontrollable nature of the antagonistic occurrence (Aubin et al., 2016). Alopecia areata impacts patients and their loved ones experiencing a lack of control over the incurable, cyclic patterns of hair loss (Hunt & McHale, 2005; Liu et al., 2016). Hopelessness as defined by Aubin et al. (2016) applies to the disease process experienced by members of the alopecia areata

community because this patient population often does not foresee the potential for a positive outcome through reliable treatment options for this autoimmune disorder (Hunt & McHale, 2005; Liu et al., 2016).

Hopelessness occurs after treatments prove ineffective for this incurable disease (Hunt & McHale, 2005). Treatment uncertainty limits a patient's sense of hope for therapeutic measures to restore hair growth, with hopelessness worsening as treatment options fail and hair loss appears permanent (Liu et al., 2016). The dismissive attitude from the healthcare community frequently rejecting the emotional severity of the loss of hair promotes self-doubt and guilt for patients with this disease (Liu et al., 2016).

Hussain et al. (2017) reported the results of a survey study supporting the value of complementary and alternative therapies for alopecia areata. Complementary and alternative therapies were defined as allopathic treatments that included biofeedback, cognitive behavioral therapy, and support group use (Hussain et al., 2017). The study utilized a 13-item electronic survey gathering descriptive data as well as patient use and satisfaction with traditional medical interventions and nonmedical interventions (Hussain et al., 2017). The convenience sample included 1,184 participants who responded to the research survey posted on the National Alopecia Areata Foundation's research site (Hussain et al., 2017). Hussain et al. (2017) described alternative treatments for mental health as therapy, mental health hotline, biofeedback, support groups, and physical health alternative treatments such as exercise and yoga or relaxation techniques. The survey responses for participation in alternative means of treatment and support were the following: (a) therapy, 31.2%; (b) mental health hotline, 2.4%; (c) biofeedback, 3.3%; (d) support groups, 29%; (e) exercise, 70.8%; and (f) yoga or relaxation techniques, 50.4%. Hussain et al. reported 78.1% dissatisfied with medical treatments for alopecia areata, and the literature further validated the thematic responses of patients who sought restorative resources without the guidance of the medical establishment. Patients independently sought support through alternative resources as a result of dissatisfaction with healthcare treatments (Hussain et al., 2017). The significant challenges associated with hopelessness, coping, loss, and self-concept impact the QoL for patients living with alopecia areata.

Quality of Life

QoL is frequently compromised for people living with alopecia areata as reported by a study by Dubois et al. (2010) that consisted of a sample of 60 participants 16 years old or older and diagnosed with alopecia areata for a minimum of 8 weeks, including 39 women and 21 men. The outcomes were compared with research findings that evaluated the QoL indicators for people with other skin disorders (Dubois et al., 2010). The sample size contained more women than men, potentially influencing the outcome; furthermore,

difficulty exists in the comparison of the impact of other skin diseases with the experience of alopecia areata, resulting in differing patient experiences (Dubois et al., 2010). The study shared similarities found in the literature indicating the significance of the autoimmune disorder on patients' health and QoL.

Fabbrocini et al. (2013) evaluated the QoL for people with alopecia areata by using the Dermatology Life Quality Index (DLQI) tool developed with specific questions to evaluate the QoL markers (Fabbrocini et al., 2013). The DLQI is a reliable measurement tool but fell short of collecting alopecia-areata-specific data (Fabbrocini et al., 2013). The Alopecia Areata Quality of Life Index (AA-QLI) is a measurement tool tailored to collect QoL data specific to alopecia areata (Fabbrocini et al., 2013). The AA-QLI tool was found reliable for evaluating disease-specific influences on QoL; however, information supporting the reliability and validity of the AA-QLI is not available (Fabbrocini et al., 2013). The sample consisted of 50 participants, 39 women and 11 men, living with alopecia areata for 6 months or more (Fabbrocini et al., 2013). The results revealed the negative influence of this disease on the patients' QoL causing difficulties with self-esteem, self-concept, and social interaction (Fabbrocini et al., 2013).

The AA-QLI tool is beneficial for healthcare providers caring for this patient population. The sample contained more women than men, which could influence the outcome if women struggle with hair loss more than men. The study neglected to depict the degree of hair loss accurately, only reporting that hair loss occurs on the scalp and the face (Fabbrocini et al., 2013). The authors recognized the importance of sensitive care delivery and the benefit of psychological support; however, the investigators reference the biologically benign attributes of the disorder.

Self-blame contributes to the worsening of psychological distress for patients with other dermatological conditions (Fortune et al., 2000; Willemse et al., 2019). Willemse et al. (2019) used QoL measures to study the impact of alopecia areata on the individual's life to evaluate the existence and influence of coping strategies. The data were gathered from participants via an online survey through social media and support groups available in both English and Dutch languages and was completed by 243 participants meeting the inclusion criteria of being 16 years old or older and having been diagnosed with alopecia areata by a dermatologist or a general practitioner (Willemse et al., 2019). The sample consisted of participants, namely, $n = 60$ from the United States, $n = 60$ from the United Kingdom, $n = 38$ from the Netherlands, $n = 28$ from Canada, and $n = 15$ from Australia (Willemse et al., 2019). The tools used to gather data included the DLQI, which is a QoL measurement tool for people living with dermatological conditions such as vitiligo or psoriasis (Willemse et al., 2019). The DLQI consists of 10 activities to score related to feelings associated with activities such as school or work, treatment, and relationships using a 4-point

Likert scale with scores of 0 = *no effect* to 3 = *very much of an effect*, with questions related to skin replaced with the term *alopecia* (Willemse et al., 2019). The QoL specifically related to alopecia areata included five categories from no effect (0–1) to an extremely large effect (21–30), noting the internal consistency was high with a Cronbach's alpha = .87 (Hongbo et al., 2005; Willemse et al., 2019, p. 1463). The authors gathered data related to illness perception using the eight-item Brief Illness Perception Questionnaire to measure eight cognitive and emotional areas of an individual's illness that included consequences, timeline, personal control, treatment control, identity, coherence (understanding), emotional representation, and concern (Willemse et al., 2019, p. 1463).

Willemse et al. (2019) gathered data about the coping strategies using the Brief-COPE that covered 14 dimensions of coping by using two items each to ask participants how they coped with alopecia areata since their diagnosis (Cartwright et al., 2009; Carver, 1997). A Likert scale ranging from 1 = *I have not been doing this at all* to 4 = *I have been doing this a lot* was used to evaluate coping to categorize the coping into the strategy groups of problem-focused coping, active emotional coping, and avoidant coping with a Cronbach's alpha of .80–.82 (Cartwright et al., 2009; Willemse et al., 2019). The coping categories were defined as problem-focused coping that included active coping, planning, religion, and instrumental support; active emotional coping that included venting, positive reframing, emotional support, humor, and acceptance; and avoidant coping that included self-distraction, denial, behavioral engagement, self-blame, and substance use (Cartwright et al., 2009; Willemse et al., 2019, p. 1464).

The statistical analysis investigated the relationship between illness perceptions and QoL and the role of coping in illness perceptions and the relationship with QoL through regression analysis (Willemse et al., 2019). The data analysis indicated that there was an association between the perception of illness and the QoL, revealing that the QoL was impaired for individuals who believed in stronger disease consequences and for those who showed avoidant coping ($p < .001$) and less active emotional coping ($p = .007$; Willemse et al., 2019). Willemse et al. (2019) reported the results were comparable with previous research by Tucker (2009) who revealed a compromised QoL for people living with alopecia areata in addition to referencing studies by Chung et al. (2014) and Ingordo et al. (2013), who reported impaired QoL for people diagnosed with conditions such as vitiligo and psoriasis.

DISCUSSION

In summary, the outcome of the literature exploration reflects research from the areas of dermatology, psychology, and internal medicine, revealing numerous difficulties experienced by patients diagnosed with alopecia areata. Bhargava et al. (2015) reported the results of a clinical review of alopecia areata specific to adolescents and indicated

that, although the condition did not cause mortality, therapeutic interventions are necessary to assist with the psychosocial impact of the disease. Patients struggle with the vulnerability caused by the transitions of health with patterns of hair loss resulting from the unpredictable nature of the disease. The healthcare community recognizes the significant impact of alopecia areata on the patient's physical and emotional health (Liu et al., 2016). The nursing profession pursues research to promote best practice and improve patient outcomes; however, nursing research falls short on the topic of alopecia areata. This autoimmune disorder causes a significant psychological impact on people living with the disease. Individuals diagnosed with the condition experience the unique phenomenon of living without hair. The literature review indicates the need for further investigation of the essence of living with this diagnosis and cyclic patterns of hair loss resulting in the health-illness transition from one stable state of health to another state of health. ■

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