The Lived Experience of Alopecia Areata

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Background and purpose. The autoimmune disorder alopecia areata results in the reported life altering experience of living without the defining characteristics of hair (Hunt & McHale, 2005). AA describes a form of hair loss that is unpredictable and has no cure and it affects 6.5 million people in the United States and 145 million people worldwide (National Alopecia Areata Foundation, 2015). The literature is not clear on the lived experience of having alopecia areata for adult men and women. Nursing research falls short in understanding the impact of the alopecia areata. This autoimmune disorder causes a significant psychological impact on people living with the disease facilitating episodes of loss and hopelessness affecting self-concept and coping during transitional episodes of health associated with hair loss (Hunt & McHale, 2005; Liu, 2016; Welsh & Guy, 2009).

This research study examines the knowledge possessed by individuals living with this disorder for the development of nursing therapeutics, support services, and sensitive provider resources. This research explores the essence of the experience of living without hair and elicit potential interventions and support services that patients with this condition will find helpful.

Methods. The research question is “What is the lived experience of alopecia areata for adult men and women 19 years of age and older?” The method is a qualitative study based on descriptive phenomenology as influenced by Merleau-Ponty with the application of Colaizzi’s (1978) procedural steps for data gathering and analysis. He notes the human body remains fundamental to the experience of human existence which, recognizes the disturbance between the body and the work significantly impacting the human experience; therefore, this philosophical approach provides direction for seeking the knowledge of the lived experience of individuals experiencing unpredictable hair loss from alopecia areata (Pollio et al., 1997; Thomas, 2005). The theoretical framework of Meleis’ Transitions Theory (2000) provides the conceptual perspective of vulnerability arising from each transitional phase of hair loss.

Sample and Setting. A total of 15 Participants, 12 women and 3 men, were recruited via contact with the National Alopecia Areata Registry (NAAR) associated with the National Alopecia Areata Foundation.

Data Gathering and Analysis. The interview took place after obtaining a signed, informed consent, demographic data sheet, and Alopecia Areata Symptom Impact Scale. The participants were recontacted for a second interview to clarify and expand on information from the first interview. The essential themes emerging from the data are:

- Coping with a life-changing diagnosis
- Managing the unmanageable
- Progression through a never-ending journey
- Disconnecting with Health Care Providers
- Finding my Own Support

Discussion. Information remains elusive about the experience of living with AA. The significance of this study far extends nursing science with the potential for interdisciplinary
application to dermatology, health psychology, and education. This research explored the essence of the experience of living without hair and elicited potential interventions and support services that patients with this condition will find helpful.

Title:
The Lived Experience of Alopecia Areata

Keywords:
Alopecia Areata, Health Care Resources and Qualitative, Phenomenology Research

References:

Abstract Summary:
Alopecia Areata is an autoimmune disorder that impacts 6.2 million Americans and 142 million people worldwide. “The Lived Experience of Alopecia Areata” is a qualitative, phenomenological study that explored the essence of the experience of living without hair for the development of nursing therapeutics, support services, and sensitive provider resources.

Content Outline:
1. Research Title: “The Lived Experience of Alopecia Areata”
   A. Introduction
2. Background and purpose.
   A. Alopecia Areata
B. Development of Nursing Therapeutics

3. Methods
A. Qualitative, Phenomenology Study Explored the experience of living with Alopecia Areata.

4. Sample and Setting.
A. A total of 15 Participants, 12 women and 3 men.
B. Setting in the community recruited via contact with the National Alopecia Areata Registry (NAAR) associated with the National Alopecia Areata Foundation.

5. Data Gathering
A. Preliminary Interview Process; IRB.
B. Demographics; Descriptive Statistics.
C. Interview Process

6. Analysis
A. The essential themes emerging from the data are:
   - Coping with a life-changing diagnosis
   - Managing the unmanageable
   - Progression through a never-ending journey
   - Disconnecting with Health Care Providers
   - Finding my Own Support

7. Discussion
A. Results
B. Application
   1. Provider, Patient, and Family Resources.
   C. Future Studies
   1. Men
   2. Women
   3. Parents of Children with Alopecia Areata
   4. Alopecia Areata, Universalis, Totalis

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Author Summary: Professional nursing practice with 23 years experience specializing in adult health in the areas of critical care and vascular access. A nurse educator in academia with experience teaching clinical or didactic courses in a baccalaureate nursing program for 8 years. Research and scholarship pertains to the autoimmune disorder, Alopecia Areata for the purpose of providing education, developing support services, and sensitive care delivery for this patient population.