

FAMILY SYSTEM AND ALOPECIA AREATA: A PHENOMENOLOGICAL
STUDY OF FAMILY MEMBERS' LIVED EXPERIENCES

A DISSERTATION

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY
IN THE GRADUATE SCHOOL OF THE
TEXAS WOMAN'S UNIVERSITY

DEPARTMENT OF FAMILY SCIENCES
COLLEGE OF PROFESSIONAL EDUCATION

BY

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DENTON, TEXAS

MAY 2016

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DEDICATION

To Nathaniel, my most beloved husband and best friend, thank you for your enduring love and support throughout this challenging process. Your love and support have encouraged and inspired me to continue the race towards the prize of the high call. I pray our precious Lord and Savior, Jesus Christ, will continue to be our guide and strength throughout our lives as one. I love you honey! You are and will always be, MY FOREVER LOVE!

ACKNOWLEDGMENTS

Pursuing this journey has offered its challenges and also its successes. I would not have been able to complete this degree without my faith in my Lord and Savior, Jesus Christ. With the help of my Heavenly Father, I was allowed to press on to reach the end of the race and receive the heavenly prize for which God, through Christ Jesus, called me (Philippians 3:14).

Thanks to each family member who so graciously opened their homes and their hearts to share with me the challenges and victories they have experienced with a loved one diagnosed with alopecia areata. I will be forever grateful and honored by your stories.

A heartfelt thank you, to my lovely sister Frankie, my cousin Diane, and my five amazing children, Nathaniel Jr., Shannon, Wandtrice, Brandon, and Khristian. No one could have understood the challenges I have faced throughout my life as a person with Alopecia Universalis, yet each of you loved the “true me.” Your love and support were the catalyst for me to pursue this doctoral degree and to research family members of those diagnosed with alopecia areata. I will forever be grateful for your phone calls, your special meals, huge hugs, and countless laughs! Without your unending love and support, my frustrations and uncertainties would have delayed this process and perhaps ended it altogether. I am truly blessed to have each of you in my life! Thanks for not only supporting me, but allowing me to share in your lives, your partners’ lives, and with your beautiful children. I will forever be grateful for each of you! United we stand!

My friends, who have prayed for me, remained attentive to my needs, listened to my complaints, and cheered me on! Words cannot express how truly thankful I am to have each of you in my life. You celebrated all the little accomplishments along the way with me, allowing me to keep my eyes on the prize!

A special thank you to my peer reviewer, Annemarie, for your consistent support, your willingness to have a listening ear, the countless lunches to discuss my study, and your faithfulness to our Lord and Savior, Jesus Christ! Annemarie, you will forever be “my school daughter.” Keep striving towards success dear one! Also, to my Texas Woman's University peers who have been through this grueling process with me, Thank you! Many of you have survived the challenges of the pursuit towards your degree and are now called Drs.!! To those who are behind me, keep striving towards a successful future. You can do it!

My chairperson, Dr. Linda J. Brock, a heartfelt THANK YOU! No one could understand my journey more than you. There were countless days of crying many tears of joy and sadness in your office, and you were ALWAYS calm and offered me a light of hope! I will forever be appreciative for your encouraging words, continued coaching, soft correcting, and maintaining professionalism! I am truly, truly thankful for you. Also, to my committee members, Dr. Joyce Armstrong and Dr. Sarah Woods, thank each of you for your willingness to instruct and guide me. The journey has been tough, but each of you have encouraged and believed in me, for which I am sincerely grateful!

Last but not least, my precious husband, Nathaniel, Honey, you have walked this journey with me. Not only have I obtained the completion of this degree, but believe you too have achieved an honorary Ph.D., in my heart, my soul, and my innermost being. Thank you, my FOREVER LOVE, for your consistent prayers, waking in the late hours to talk and offer a listening ear, for wiping away my tears, encouraging me to keep pressing on, and celebrating my successes along the way! Thank you for completing household chores, working late hours to support our family, driving to Denton each night to support me during Comprehensive exams, giving me confidence during my dissertation process, and believing in my dream to help other alopecian families! These are just a few of the many things you have done over the last 7 years, while supporting me on this journey. I know that this has been overwhelming for you at times, but thank you for never giving up on me. You and Me, honey! You are and will always be, MY FOREVER LOVE!

ABSTRACT

BARBARA A. BUCHANAN

FAMILY SYSTEM AND ALOPECIA AREATA: A PHENOMENOLOGICAL STUDY OF FAMILY MEMBERS' LIVED EXPERIENCES

MAY 2016

This qualitative phenomenological study examined the lived experiences of family members of individuals diagnosed with alopecia areata, a chronic autoimmune disease, which destroys the growth of hair follicles on the scalp and the body. Currently, alopecia areata affects approximately 4.7 million individuals in the United States (Kalabokes & Besta, 2001). General systems theory was used to offer a framework for explaining and understanding the systemic impact of the disease within the family. The researcher interviewed 15 family members of those individuals diagnosed with alopecia areata who volunteered for this study. Semi-structured interviews were audiotaped, transcribed word for word, and analyzed to establish themes. Three themes and six subthemes emerged from the data: (a) Challenges of Emerging Alopecia Areata with subthemes Seeking a Diagnosis, Experiencing Public Scrutiny, and Is it Stress?; (b) Transitioning to a New Normal with subthemes Choosing Wigs or Not?, Financial Strain, and Supportive Relationships; and (c) Hope for Future Medical Advancements with no subthemes. Selected participants responses were included to illustrate the identified themes.

The results of this study were compared to other autoimmune diseases and the family system and the conclusions were identified. Clinical implications and limitations of the study are discussed, as well as recommendations for future research.

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CHAPTER I

INTRODUCTION

Research studies conducted by Kalabokes and Besta (2001) reported that alopecia areata does not discriminate and any age group, ethnicity, or gender can acquire the disease. In fact, alopecia areata affects approximately 2% of the global population, which includes approximately 4.7 million people in the United States alone. Alopecia areata is a chronic autoimmune disease that destroys the growth of hair follicles on the scalp and the body of those impacted by the disease (Hunt & McHale, 2005a; 2005b). Those who develop the disease are generally in good health when they are diagnosed. However, Huang, Mullangi, Guo, and Qureshi (2013) reported that other autoimmune diseases such as thyroid disease, diabetes, inflammatory bowel disease, systemic lupus, rheumatoid arthritis, psoriatic arthritis, atopy (i.e., asthma, eczema, and contact dermatitis), and mental health problems (i.e., depression or anxiety) have been diagnosed in individuals with alopecia areata and/or their family members. Gilhar and Kalish (2006) proposed that the disease could be predisposed and that other elements, such as a viral infection or environmental conditions may have been the catalyst for the condition to form.

The National Alopecia Areata Foundation (2016) reported individuals with alopecia areata usually develop circular patches on the scalp at the start of hair loss and eventually may experience the loss of hair entirely over the scalp and body. Researchers also proposed the autoimmune disease may destroy hair follicles in patches or could

affect the total growth of hair on the entire scalp (alopecia totalis) and whole body (alopecia universalis) of men, women, and children of all ages (Colón, Popkin, Callies, Dessert, & Hordinsky, 1991; National Alopecia Areata Foundation, 2016; Tucker, 2009).

Price (1991) reported the onset of alopecia areata generally occurs before the age of 20, and a higher percentage of those diagnosed are female. Hunt and McHale, (2005a, 2005b) reported men with alopecia areata might have different experiences with the loss of their hair as compared to women. Men's experiences may differ due to societal acceptance of male baldness, causing many men to adapt to the hair loss differently than do women. Hunt and McHale further stated women's experiences differ from men's because of the societal pressures projected towards women. In essence, societal pressures about a woman's hair have defined her sense of beauty.

Prickitt, McMichel, Gallagher, Kalabokes, and Boeck (2004) proposed that although alopecia areata is not a life threatening disease, the initial onset of hair loss may cause other emotional stresses for the individual and bring about a disturbance within his or her personal life. A myriad of cultures view the presence of hair and its beauty as a meaning of sexuality and attractiveness. Unfortunately, this attachment to hair and its representation could alter one's self-esteem and body image (Anderson & Johnson, 1994; Burt, 1995; Carpenter & Brockopp, 1994; Frank-Stromborg & Wright, 1984). Hair is an attribute in which a woman's sense of femininity, beauty, and attractiveness are founded (Williams, Wood, & Cunningham-Warburton, 1999). Hunt and McHale (2005b)

postulated that women experiencing hair loss may believe they do not fit into the societal norms or expectations, which may lower the woman's self-esteem and self-confidence.

Statement of Problem

Alopecia areata is an autoimmune disease that affects approximately 4.7 million individuals within the United States. The onset of the alopecia areata can occur at any age, and for any ethnicity or gender of an individual diagnosed with the condition (Kalabokes & Besta, 2001).

The effects of alopecia areata can impact individuals due the physical changes they may experience. Research has shown that women experiencing a physical change in appearance may also experience a change in their intimate relationships with their partners and in social interactions with others (Tucker, 2009). Pickard-Holly (1995) stated alopecia areata could also be linked to both men and women experiencing signs of depression, loss of self-confidence, and a sense of humiliation. While there has been much research on the biopsychosocial etiology and outcomes of alopecia areata (Colón et al., 1991; Hunt & McHale, 2005a, 2005b; Mayo Clinic Staff, 2011; National Alopecia Areata Foundation, 2016). There is limited empirical research that evaluates the autoimmune disease and its impact on family members of individuals diagnosed.

Therefore the purpose of the present study was to explore the lived experiences of family members of individuals diagnosed with all three forms alopecia areata. A qualitative approach was implemented in an effort to gain an understanding of diagnosed individuals' family members. The following research question guided this qualitative

study: What is the lived experiences of family members of individuals diagnosed with alopecia areata?

Theoretical Framework

The theoretical framework utilized in this study was the systems theory. The systems theory was originally founded by biologist Ludwig von Bertalanffy (1968). He proposed systems theory is a complex of elements interacting with their environments, which sheds light on the organization and interrelatedness of human interactional patterns. von Bertalanffy stated that all parts of the system are interrelated and that change in one part of the system is directly connected with all other parts of that system changing. He further stated that the system is similar to a state of balance (homeostasis) that maintains the system for which there are periods of change and stability that sustain balance within the system (von Bertalanffy, 1968).

The systems theory is vital with understanding the interconnection of family members and allows mental health professionals to view the family as a whole unit and not isolate the identified patient as a single individual, unrelated to the system (Patterson, 2014). The systems theory is suitable for the theoretical framework of this phenomenological study, to examine the interactional patterns of the family members' and gain understanding about their lived experiences, after a member has been diagnosed with alopecia areata.

Methodological Approach

To achieve the purpose of this study, the researcher implemented the phenomenological approach. Specifically, the researcher examined the meaning of human experiences concerning a particular phenomenon (Creswell, 2007). Denzin and Lincoln (2003) proposed "...[P]henomenological analysis is principally concerned with understanding how the everyday, intersubjective world (the life world, or *Lebenswelt*) is constituted. The aim is to grasp how we come to interpret our own and others' action as meaningful..." (Denzin & Lincoln, 2003, p. 297). The principle purpose of this study was to explore the lived experiences of family members of individuals diagnosed with alopecia.

Definition of Terms

For the purpose of this study, the following terms will be utilized.

1. Alopecia Areata: The most common distinction of the autoimmune disease is that it causes the loss of hair on discrete areas of the scalp. Hair loss to the scalp appears as small, round, smooth patches of various sizes (National Alopecia Areata Foundation, 2016; Tucker, 2009).

Alopecia areata is the mildest form of the condition and could advance into two other forms including:

Alopecia Totalis: The total loss of hair on the scalp, with evidence of hair on other parts of the body remaining (National Alopecia Areata Foundation, 2016; Tucker, 2009).

Alopecia Universalis: The rarest form of alopecia areata that causes the loss of hair over the entire body (National Alopecia Areata Foundation, 2016; Tucker, 2009).

2. Family member: Anyone related by blood or marriage such as parents, siblings, and significant others.

Alopecia areata is a chronic autoimmune disease that destroys the growth of hair follicles on the scalp and body of those diagnosed. There are three stages to the disease which includes alopecia areata, alopecia totalis, and alopecia universalis (National Alopecia Areata Foundation, 2016). Alopecia areata was identified in the study as the overarching condition that also includes both alopecia totalis and alopecia universalis.

Assumptions

The following assumptions were made in the present study.

1. Participants will respond openly and honestly about their experience as family members of those diagnosed with alopecia areata.
2. There may be discrepancies among family members' experiences.
3. The researcher will be aware that as a participant-observer, she will both impact the study and be impacted by it.
4. The researcher will be aware of her own preconceived ideas and interpretations. The researcher will place those ideas and interpretations aside.

Delimitations

The following delimitations were applied to this study.

1. Participants were 18 years or older and were family members by blood or marriage of those individuals who were diagnosed from early childhood to adulthood with alopecia areata.
2. Participants were both African American and Caucasian ethnic groups.
3. Participants were willing to volunteer for a face-to-face or telephone interview.

The Researcher as A Person

According to Patton (2002), in qualitative studies, the researcher as a person becomes an intricate part of the research process. Denzin and Lincoln (2003) also proposed that within a qualitative phenomenological study, the researcher becomes a part of the study and is involved with the participants during this process. More importantly, during this scientific inquiry, the researcher realizes that the participant's lived experience is an interpretation only, and is viewed through the lens of the researcher's biases, age, gender, culture, and knowledge of the disease (Creswell, 2007). These biases may guide and constrict the study's results. As the study instrument, the researcher is obligated and has a responsibility to acknowledge his or her interpretation.

I am a Marriage and Family Therapy doctoral student at Texas Woman's University in Denton, Texas. I have worked with families for over 17 years as a mentor, educator, and mental health professional. I have experienced hair loss for over 42 years

and have the diagnosis of *Alopecia Universalis*. I am curious about the lived experiences of family members of others diagnosed with alopecia areata. Moreover, I hope that sharing the experiences of the families may broaden the understanding of this phenomenon and benefit the field of family therapy.

Summary

There is substantial research that confirms alopecia areata as an autoimmune disease that affects individuals on a global level. The purpose of this study was to explore the lived experiences of family members of those diagnosed with the alopecia areata. The systems theory suggests that family members affect each other. But no research has been found that examined the lived experiences of family members of those diagnosed with the alopecia. Therefore, the systems theoretical framework will be utilized for this qualitative phenomenological study to discover the family members' experiences. Ideally, this research will offer more knowledge about this phenomenon and offer insight to both medical professionals and marriage and family therapists who may advise clients diagnosed with alopecia areata and their families.

CHAPTER II

LITERATURE REVIEW

Tucker (2009) defined alopecia areata as a chronic autoimmune disease that is distinguished by a patchy or abnormal loss of hair. Individuals normally recognize the loss of hair on the scalp as a small circular or oval appearance. Those who seek medical assistance have concerns about its inception and are curious as to whether the loss of hair could spread to other areas of the body. Some may encounter a full hair loss to the head which is called alopecia totalis, while others experience the loss of hair to the scalp, face, and body, known as alopecia universalis.

Colón et al. (1991) stated that the loss of hair is unpredictable for those experiencing the early onset of the disease. The researchers further reported some individuals with alopecia areata might recover hair (in intermittent episodes) throughout their lives. Yet, others may not experience any new growth of hair, which may cause a sense of confusion, loss, and shame. Prickitt et al. (2004) confirmed those who experienced the loss of hair were emotionally devastated and believed their lack of hair negatively influenced their self-esteem, body image, and/or their self-confidence.

Hunt and McHale (2005a, 2005b) postulated that hair loss for both men and women could be detrimental, especially considering the difficulty of societal expectations. Tucker (2009) reported those individuals with hair loss were impacted negatively because of the societal belief that beauty is based upon one's hair. As a result,

those who experienced hair loss felt isolated due to medical care, personal identity, and social acceptance (Hunt & McHale, 2005a, 2005b; Tucker, 2009). In an effort to understand the autoimmune disease and its societal impact, earlier studies are reviewed here to offer better insight into the experiences of those living with the disease.

Studies of Alopecia

This chapter first reviews studies of the autoimmune disease, more specifically examining its influence upon the individual within the medical, personal, and social dimensions. Second, because limited research was found which examines alopecia areata and its impact upon the family members, current studies on other autoimmune diseases are reviewed to gain insight into the systemic effects on families of each disease.

Medical Care

The Mayo Clinic Staff (2011) reported that hair loss might be caused by many factors including genetics, male pattern baldness, and alopecia areata. There are several treatments available to assist individuals with the possibility of hair regrowth. According to the Mayo Clinic (2016a), hair loss due to alopecia areata could regrow without any treatment needed. However, the effectiveness of the treatment depends upon the severity of the loss of hair, the length of time of the hair loss, and an individual's response to medical treatment. Several recommendations are offered for treatment of hair loss that includes medications and/or different surgical procedures.

In contrast to the Mayo Clinic (2016a), the American Academy of Dermatology (2011) reported that alopecia areata is not a condition that can be cured. They offered

several treatments that could be implemented to assist with possible regrowth of hair in an affected area; however, the probability for regrowth is slim. Treatments that could be implemented for alopecia areata include prescription medications, surgery, and alternative methods.

Prescription medications. Corticosteroids are anti-inflammatory drugs that suppress the immune system. The corticosteroid can be injected into the affected area, taken as a pill, or rubbed into the area. The recommendation for injections is every 3-6 weeks, with regrowth generally beginning around the fourth week of treatment. The rub appears to be less effective than the injection and the pill tends to have side effects (Mayo Clinic Staff, 2011). Utilizing pills as a form of treatment for persons experiencing hair loss may be somewhat effective. However, the treatment does not offer a permanent solution.

Surgical treatment. Hair transplant is a surgical procedure that includes taking hair plugs from patches of hair and replanting them in the bald areas of the head or body. The procedure may take several sessions, but does not promise to be effective. This procedure is high risk, and could include infections or scarring. Another surgical procedure is scalp reduction. Scalp reductions include removing portions of the scalp that are bald. After the scalp is removed, the space is closed with portions of the scalp that has hair. The reduction can be combined with hair transplantation for a natural looking hairline, especially for those with extensive hair loss. The procedure is high risk, with potential infection or scarring. These procedures could be quite invasive and must be

implemented under strict physician care. Yet, there are other alternative methods that are non-invasive and do not require medical treatment from a physician (Mayo Clinic Staff, 2011).

Alternative methods. Other methods to deal with hair loss include utilizing coverings for the head such as: wigs, caps, hats, and scarves. Wearing a head covering protects the scalp from harmful UV rays and damage to the skin. It is important to note that these alternatives do not hinder the growth of hair and may be a good choice for those who experience excessive hair loss (Mayo Clinic Staff, 2011).

While both the Mayo Clinic Staff (2011) and the American Academy of Dermatology (2011) offer suggestions for medical treatments for individuals with alopecia areata, neither propose treatments by mental health professionals who could assist them with their emotional and/or psychological needs. According to Hunt and McHale (2005a), individuals diagnosed with alopecia areata desire for the medical community to have a greater understanding about the condition. They reported that the participants felt dismissed by their physicians when they had concerns about their hair loss and stated their physicians would discuss their medical treatment, but would disregard their psychological needs. Lastly, they had difficulty finding physicians who would validate their emotional concerns or offer advice in regards to offering a referral for a mental health professional.

Personal Identity

Hunt and McHale (2005a) conducted a two part study that examined the psychological impact of alopecia. The first part of the study included 162 participants that spontaneously gave a written account to their experiences about the impact of the disease both personally and socially. The second part of the study included recruiting a different sample of 34 participants who responded with their written experiences by email to the study. All participants' ages ranged from 12 to 93, with some parents writing answers for the minor children. Each participant was encouraged to respond about their experiences and no prompts were given. Using a grounded theory approach, the researcher's results were reported in three categories: personal, social and medical experiences. The researchers proposed that a female's personal identity had a direct link to her hair and its representation of beauty. In comparison to males, a female's hair is a symbol of her sense of femininity, sexuality, attractiveness, and personality. Females who lose their hair display a sense of loss that sometimes adversely influences their self-esteem and body image. In a comparison of females with alopecia areata and those without, those who have alopecia areata displayed a poorer self-image. Lastly, after the loss of hair many of the female's self-perception decreased (Hunt & McHale, 2005a).

Self-esteem/body image. Individuals with alopecia areata are emotionally impacted due to the loss of hair. Tucker (2009) reviewed literature from six different data bases searching for areas such as psychological and psychosocial stresses, body image, self-esteem, women, and hair loss of those diagnosed with all three forms of alopecia

areata. Tucker's search revealed 40 articles that potentially met the criteria for the study. Those studies that did not meet the criteria were excluded and 19 primary articles were examined. From primary studies there were 518 male and 753 female with a total of 1271 participants. The results for the literature review revealed individuals diagnosed with alopecia areata were negatively impacted psychosocially and emotionally.

Tucker (2009) further reported the participants had increased levels of depression and anxiety. Those individuals who lost facial hair, such as eye lashes and eyebrows, also had problems with their identity and identity change because these features help define a person's face. The participants described low self-esteem, a reduction in their quality of life, and a negative view about their body image. The data reviewed highlighted that those individuals with alopecia areata experience psychological and/or emotional stresses, which created also personal and/or social problems. Specifically, the study revealed that over half of the participants stated the disease negatively affected their self-esteem and increased levels of depression, anxiety, phobic reaction, and paranoia (Tucker, 2009).

Social Acceptance

The personal identification of self could be directly correlated to social interaction with others. Schmidt, Fisher, Chren, Strauss, and Elsner (2001) reported that individuals with alopecia areata might have difficulty interacting with others due to social anxiety. Social anxiety is described as fear of being humiliated or judged by others in a social setting (Colón et al., 1991; Schmidt et al., 2001). Curlette and Kern (2010) agreed on the

importance to belong in the Journal of Individual Psychology, stating individuals have a need to be accepted within society, especially within their family of origin. Those individuals from a supportive family of origin as a child may also develop the tools to adapt well socially as an adult. Hunt and Mchale (2005b) reported those who experience social anxiety avoid others and may fear that they may be ridiculed and treated unfairly. Fearing interaction with others could lead to isolation and higher levels of depression within the family unit and work environment. Tajfel (1982) reported the social identity theory presumes an individual's sense of identity is maintained by relating to others within a social setting.

Societal influences. Hunt and McHale (2005a, 2005b) explained that there are several differences in how males and females may be challenged by the disease. Males revealed they have shame and difficulty in public places because of their hair loss. Adolescents and children also experience trauma with the loss of their hair, in particular to ridicule from their peers, especially in school settings. Lastly, females found it to be more difficult having alopecia areata due to the societal views of bald women; societally, bald women are viewed as less attractive and/or appealing as a prospective mate.

Hunt and McHale (2005b) reported that females experienced emotional stress at higher levels than males. It was observed that when young girls lose their hair they exhibit immense signs of sadness and a heightened sense of shame. The probability for girls expressing sadness and shame may be linked to their hair playing a large role in the girls' self-image and self-esteem. The same might be true for women who have alopecia areata

coping in a society which is focused on body image and self-esteem. Hunt and McHale explained that females may have more difficulty coping with hair loss than males. Mostly, because it may be fashionable for males to shave their heads and be bald, however the same societal message is not allowed for females.

Personal relationships. According to Hunt and McHale (2005a; 2005b), personal relationships are vital for individuals with alopecia areata. Encouraging relationships with friends and families were essential for their support and well-being. It was imperative for individuals with alopecia areata to develop positive personal relationships with friends and family in order to construct an optimistic sense of identity.

Maintaining positive social support systems allows individuals to cope with alopecia areata better. Support is not only mediated by personal relationships with partners, friends, and family, but it is also important for individuals with alopecia areata to maintain positive relationships with their medical professionals (Hunt & McHale, 2005a, 2005b). As a result, these studies have shown individuals with alopecia areata have a greater chance of coping with the disease when they have a positive social support system.

Although these studies have suggested personal and professional relationships are important to the person diagnosed with alopecia areata, there has been little to no research found that examined the family system of those diagnosed with alopecia areata. Some, research has examined the lived experiences of family members with other autoimmune disorders.

Studies of Other Autoimmune Diseases

Research on autoimmune diseases other than alopecia areata, such as celiac disease, juvenile rheumatoid arthritis, and Parkinson's disease, has examined the effects of the illness on the family. More specifically, research on these illnesses has examined the influence of the disease within the parental/child subsystems and couple relationships. The following research highlights other autoimmune diseases to examine how the disease impacts the family members' lives. Other diseases reviewed include celiac disease, juvenile rheumatoid arthritis, and Parkinson's disease.

Celiac Disease

Celiac is an autoimmune disease which affects approximately 1% of the population within the United States (Bacigalupe & Plocha, 2015). The disease causes a response to gluten within the digestive system of the individual. Gluten is a protein found in grains such as wheat, barley, and rye. The ingestion of gluten causes an immune reaction in those individuals with celiac. Individuals may experience a variety of symptoms including upset stomach, bloating, diarrhea, nausea, and vomiting. Treatment for the disease includes implementing a restricted gluten-free diet (GFD). This is a complex strategy because it may require an avoidance of cross-contamination due to trace amounts of gluten that could cause intestinal difficulty (Bacigalupe & Plocha, 2015).

Bacigalupe and Plocha (2015) conducted a qualitative study examining the systemic affects of celiac disease upon the family system. The purpose of the qualitative study was to examine barriers families may experience with children who have celiac and

the strategies they implement for a gluten-restricted diet. The investigation recruited 10 families, within the Northeast United States region, with children between 6 and 12 years of age. Bacigalupe and Plocha requested each child must have been diagnosed with celiac by either an endoscopy, blood work, or both to participate in the study.

Bacigalupe and Plocha (2015) reported the interviews were conducted within a 60 to 90 minute timeframe at an agreed upon location. It was also reported that of the 10 family interviews, only 1 interview included the mother and father of the child. The other interviews included only the mother of the child diagnosed with celiac. The narrative and grounded theories were used to analyze the data. Each interview was transcribed and NVivo 9 software was used to code the data. The interview transcriptions revealed three primary barriers to diet adherence including: “social isolation, gender inequality, and misunderstandings about celiac disease” (Bacigalupe & Plocha, 2015, p. 4).

These results revealed the parents felt isolated due to the difficulty of taking their child to social events where food is served. They reported it was difficult because other friends and family members did not understand the detrimental impact gluten could have upon the child. Also, the parents reported they could not be spontaneous and for that reason they were consistently aware of the need to *plan* for social events. Secondly, the results revealed that the mothers believed there were gender inequalities since the responsibility of the child’s care was solely placed upon them. The mothers said the fathers did not attend doctor’s visits, assist with the food selection for the home, or examine the child’s food intake. Lastly, the outcome of the study revealed there was a

misunderstanding about the disease. The misunderstanding caused concern for the parents since there was a chance of cross-contamination of food, if the child ate gluten the symptoms could be severe, and the important need to educate others about celiac. The participants of the study reported a need to have support from their family and friends, the school and community, group support, and from others who share the same dietary needs (Bacigalupe & Plocha, 2015). This research offers insight into the present study as a guide towards understanding the impact of illness within a parental-child relationship. It also reflects the need to maintain positive relationships to allow family members' the ability to cope with illness is within different social settings.

Juvenile Rheumatoid Arthritis (JRA)

Helgeson, Janicki, Lerner, and Barbarin, (2003) examined the adjustments to juvenile rheumatoid arthritis (JRA) and its relation to the family environment. The researchers examined both age and gender to determine if there was a systemic impact of JRA. They defined juvenile rheumatoid arthritis as a chronic autoimmune disease with common symptoms such as inflammation in the joints with aches, stiffness, and fatigue. Many individuals diagnosed with JRA are children the ages of 15 and younger. Helgeson et al. (2003) reported in the United States there were approximately 30,000 to 50,000 children diagnosed.

Participants in the study included 94 children and adolescents. There were 61 female and 32 males. The ages ranged from 7 to 20 years. The participants were recruited by two separate mailings through the Arthritis Foundation in Michigan and the Pediatric

Rheumatology Clinic at the University of Michigan Medical Center. Included in the mailings were a survey and a letter explaining the purpose of the research. There were 37 families recruited from the Arthritis Foundation and 56 families from the Pediatric Rheumatology Clinic. The parents completed the demographic questionnaire. Next, the children completed surveys to measure the family environment, adjustment to RA, and self-esteem (Helgeson et al., 2003)

The results of the study concluded when there was family cohesion, the child adjusted well to RA. In contrast, when the environment was conflictual the child experienced a poor adjustment to RA. When there was some family cohesion, the younger children adjusted better to RA than the older children. Lastly, the child's autonomy when adjusting to RA was dependent upon the age and sex of the child (Helgeson et al., 2003). This study offers insight into the present study because it examines the autoimmune disease and family cohesion. Those families who have positive family relationships have a greater ability cope with illness in their family environment.

Parkinson's Disease

Hodgson, Garcia, and Tyndall (2004) conducted qualitative research that examined Parkinson's disease and its influence on the couple relationship. The authors reported Parkinson's disease as a "chronic, progressive nondegenerative disease" (p. 101) that was discovered by James Parkinson in the early 1800s. Hodgson et al. (2004) reported the symptoms of Parkinson's disease are described as the presence of "resting tremors, rigidity, and bradykinesia (abnormal slowness of movement)" (p. 101). The

disease affects approximately 500,000 Americans, who are commonly diagnosed over the age of 50, with an increase in age-related prevalence up to a minimum age of 80.

The researchers used a nonrandom, purposive sampling method to identify couples to participate in the study. The participants were recruited from a Parkinson's disease support group that was located in the southeastern region of the United States. All of the 10 heterosexual couples who participated in the study were Caucasian. Of those individuals diagnosed with Parkinson's disease, the ages ranged from 46-79 (M=61.8) years of age and the caretakers ages ranged between 52-79 years (M=62.4).

Within the couple systems, 6 males and 4 females were diagnosed with PD. They reported having the diagnosis between 2 to 20 years. The researchers rated the level of severity of the disease by reviewing the five stages of Parkinson's disease. The five stages assess the onset, progression, and mortality rate of Parkinson's disease. At the time of the study, there were 2 patients in Stage 2 (later phase), 6 in Stage 3, and 2 in Stage 4. The stages range from Stage 1 (marginally noticeable) to Stage 5 (severe with a need for assistive care). Of the 10 couples, 9 couples were married and 1 couple was cohabitating. Nine couples reported having children, with 2 of the couples having children under the age of 18.

The data were collected using a qualitative phenomenological approach with the question: "What impact has PD had on your couple relationship?" The results to the study concluded with 5 thematic clusters: (a) Relationship and Disease History, each couple discussed historical information about the relationship and the onset of the disease; (b)

Impact on the Couple Relationship, couples conferred how the disease impacted the relationship both negatively and positively; (c) Impact on Self and Others, couples reflected how the disease impacted not only the relationship, but also the each person individually; (d) Connecting with Resources, the availability to resources where difficult for the couples. Each discussed a desire for the medical professionals to have better knowledge about the disease; and (e) Strategies for Survival, couples discussed how to maintain the relationship and manage symptoms of Parkinson's disease.

Hodgson et al. (2004) reviewed literature that examined chronic illness and its impact upon couples. The review revealed couples may experience difficulty expressing feelings about the illness, as well as, experiencing changes within the function of the relationship. The conclusion for couples with illnesses such as Parkinson's disease was for the couple to establish supportive relationships outside of the couple system. This study adds insight into the present study that examines couple relationships and illness.

Summary

Alopecia areata is a disease that has important effects on the personal and social lives of those living with the diagnosis. Although no studies were found that explored the systemic effects on families when alopecia areata has been diagnosed, studies of families dealing with other autoimmune disorders indicate a variety of psychological effects. The systems theory is vital with understanding the interconnection of family members and illness. The literature reviewed explored the family as a whole unit and did not isolate the person identified with the illness as a single individual, unrelated to the system

(Patterson, 2014). Research is needed to learn more about the experiences of illness and the impact it has on the family unit.

CHAPTER III

METHODOLOGY

The purpose of this phenomenological study was to explore the lived experiences of 15 family members of individuals diagnosed with alopecia. The results from this study will assist family therapists and other professionals who work with individuals diagnosed with alopecia. A qualitative methodology was chosen for this study, to invite participants to examine their lived experiences and personal insights. The qualitative research, offered the researcher a way to interpret family relationships systemically and see the larger picture (Denzin & Lincoln, 2003; Patton, 2002).

Data were collected through both face-to-face and phone interviews with 14 adult family members of those who are diagnosed with alopecia. Semi-structured in-depth interviews were conducted using one interview question, along with prompting to encourage participants to speak freely about their personal stories (Wengraf, 2001). The interviews were audio recorded for transcription.

Research Participants

The participants for this study included 14 adult family members (ages 24 to 68). Two ethnic groups were represented including African American and Caucasian. The family relationships encompassed parents, siblings, a cousin, a fiancé, and daughter-in-law of those individuals diagnosed from early childhood to adulthood with alopecia areata, alopecia totalis, or alopecia universalis.

Sampling Procedures

According to Kvale (1996), the targeted sample size should include 5-25 participants for a phenomenological qualitative research. The targeted representation for this study was 15-20 family members of those diagnosed with alopecia areata, alopecia totalis, or alopecia universalis. In qualitative studies, the sample size should be suitable to reinforce the study's purpose while maintaining the reliability of the research. Participants for this study were recruited on a local, statewide, and national level in an effort to obtain a minimum of 15 participants who have a family member diagnosed with alopecia areata.

A recruitment flyer (Appendix A) was created and, with permission, posted in multiple locations, including churches, physician's offices, websites, and Texas Woman's University in Denton and Dallas. In addition, recruitment flyers were placed in other public areas such as local grocery stores, beauty salons, and barber shops where permission was given.

Snowball sampling was also used for this study. Since snowball sampling was used, the researcher asked participants about others they may know who might have an interest in the study. Snowball sampling, also known as chain referral sampling, is similar to purposive sampling. With this method, the participants or other informants use their social networks to refer to others who may be interested and could contribute to the study. Essentially, snowball sampling allowed the researcher to recruit those populations that are hidden or not easily reached by other sampling techniques. Lastly, snowball

sampling had shown to be an effective, economical, and efficient method for qualitative studies (Creswell, 2007).

Research Design

The research design for this study utilized the phenomenological approach. This approach was chosen because it allowed discovery rather than critique (Ambert, Adler, Adler, & Dentzer, 1995). Phenomenological research emphasizes the lived experiences of individuals and offers a voice to their specific experiences through interviews (Patton, 2002). This type of research allowed the individual to describe and make sense of their personal experiences and provides a rich description of their stories (Creswell, 2007). Anderson and Goolishian (1988) proposed human systems are “meaning-generating systems” (p. 377). Sprenkle and Moon (1996) agreed that humans are meaning-making individuals, within a socially constructed paradigm. The authors were clarifying that each individual’s experiences may have multiple meanings, within a socially constructed ‘truth’ (Sprenkle & Moon, 1996). The assumption of this study was that families who have had a member diagnosed with alopecia areata have a shared experience and that each individual had generated specific meaning based upon their experiences (Creswell, 2007).

Data Collection

Participants who volunteered for the study were to contact the researcher to gain a better understanding about the purpose of the research and to clarify any questions they may have had before the interview process.

The primary method for collecting data in this phenomenological research was the interviewing process because it allowed the participants to explore their lived experiences (Patton, 2002). The interviewing process is more than asking the participants questions, as it offered a collaborative process from which rich narratives were revealed. Each interview was audio recorded for accuracy. The setting for face to face the interviews was located at an agreed upon location within north Texas and the surrounding states. In phenomenological research, Sprenkle and Moon (1996) recommended interviewing the participants in their natural setting. Phone interviews were conducted with the use of a recorder, in a quiet isolated office space.

Participants were asked to complete a demographic questionnaire (Appendix C). Participants provided their gender, occupation, race/ethnicity, state of residence, religious affiliation, relationship status, number of children, educational level, annual gross income, member of a alopecia areata organization, the type of alopecia areata of the family member, when the family member began noticing hair was falling out, and any other family members diagnosed with alopecia areata. The demographic questionnaire included a multiple choice format which participants marked the choice that best applied to them. Space was provided for clarity about the family member's loss of hair, the family relationship, type of alopecia, and other family members diagnosed with alopecia areata.

Instrumentation

In qualitative research, the interviewing process is vital towards gathering data. Most importantly, the researcher is the instrument. Creswell (2007) encouraged researchers who are developing a qualitative interview protocol to draft a central question and from that develop sub-questions. In an effort to clarify the research purpose, the researcher informed the participant that the study was centered on their personal experiences of alopecia areata in their family. For this study, one central question, an interview question, and prompting questions were implemented (Appendix D).. The research question that guided this study was:

Research Question: What is the lived experience of family members of individuals diagnosed with alopecia?

The interview question used in this study was:

Interview Question: Tell me your story.

The researcher used prompts for clarification (Appendix D).

Protection of Human Participants

The present study was approved by Texas Woman's University Institutional Review Board to protect the integrity of the participants. The participants' confidentiality was protected using a coding system. Numerical and alphabetical codes were assigned to each participant. Consecutive coding began with 1A and ended with 15J. Only the researcher has access to identifying information. The participant's name appears on the consent form only. Only the participant's code number appears on the demographic form

and transcripts. Transcripts, audio recordings, consent forms, and the list of participants who requested a summary of the study's results were kept in a locked cabinet, in the locked home office of the researcher. Only the researcher has access to the locked cabinet. All identifying data, audio recordings, and transcripts that identify the participant will be destroyed within two years of completing the study.

Participants were given the opportunity to ask questions during the recruitment and interviewing process. The researcher also asked if participants had any questions at the end of the interview. Participants were given a referral list so that they might contact a mental health professional if they chose to talk to someone about any discomfort they might have experienced as a result of the interview (Appendix E). Participants had the opportunity to contact the researcher or her advisor directly both during and after the research process via email or phone call if they needed additional assistance.

Interview Procedures

Qualitative research examines data throughout the research process until a point of data saturation is reached. According to Wray, Markovic, and Manderson (2007), data saturation is accomplished when there is no new information found. The researcher anticipated that 15-20 family members would yield a point of data saturation. The semi-structured interview (Appendix D) was central to the study, using the phenomenological approach to capture the personal meaning/experiences of alopecia areata in the lives of the family members. A semi-structured interview is open, and allows the participant to offer new ideas during the interview (Creswell, 2007).

For this study, a qualitative approach was utilized to explore the lived experiences of family members of those diagnosed with alopecia. The interviewing process was essential to the study. Therefore, the relationship between the researcher and participant included respect and neutrality. As an instrument, it was the researcher's responsibility to communicate an attitude of respect and maintain a neutral stance during the interviewing process (Patton, 2002).

The researcher has been diagnosed with alopecia universalis and began losing her hair during early childhood. The researcher's role and experiences with alopecia areata may have had an effect on the participants. The degree of openness on the part of the participants may have been dependent on their opinion of the researcher's position as a person with alopecia areata. Participants may have refrained from responses that are more critical in an effort to not insult the researcher. Alternatively, potential participants may have been reluctant to participate in the study because of their feelings about the disease.

The researcher made every effort to set aside her biases when she interviewed each family member. Yet, in all research bias is inherent (Sprenkle & Moon, 1996). In an effort to suspend the researcher's biases or preconceptions the [technique of bracketing] was used. Bracketing was used so that each participant's true experiences of the phenomenon would be revealed to the researcher (Wimpenny, 2000).

The researcher informed the participant about the research using a telephone script (Appendix F). When the participant agreed to become a part of the study, an agreed upon a location and time was established for the interview. When the appointment had

been established, the researcher arrived in a timely manner, dressed in professional attire, and presented herself as a caring professional while conducting the interview with the participant. For confidentiality, only the researcher and participant were at the agreed location. Additionally, two copies of the consent form (Appendix B), audio recorder, a writing pen, and paper for note taking were used at each interview.

Once the interview began, the researcher gave the participant the consent form (Appendix B) and answered any questions the participant had. A copy of the signed consent form (Appendix B) was given to the participant and one was kept by the researcher. Next, the demographic questionnaire (Appendix C) was given to the participant to gain information about the participants' education, ethnicity, income, spirituality, and relation to the family member diagnosed with alopecia. Lastly, the semi-structured interview guide (Appendix D) was used to gain information about the participants' lived experiences. The following question was posed: Tell me your story. Participants were asked to speak freely about their experiences and to ask questions for clarification, when needed.

Each interview was audio recorded, transcribed, and analyzed for themes. The result of each interview was reported using a narrative format. After the interview was completed, participants were given a referral list (Appendix E) for mental health professionals. Additionally, participants were asked if they wished to read the transcript. If so, the researcher agreed to contact the participant if he or she wished to correct or add

any additional information (Appendix B). No participants requested to read their transcript.

Treatment of Data

A qualitative study allows the researcher to collect narratives about participants' personal experiences. It was important for the researcher to analyze, interpret, and present data in an effective and efficient manner. Piercy and Benson (2005) stated, "If a researcher presents data without analysis, the data excerpts necessarily will be partial, in that they will focus on one aspect of the phenomenon being studied" (p. 108). Once the researcher completed each interview, she arranged and organized the data by reading and transcribing each interview verbatim.

Creswell (2007) proposed that data analysis for phenomenological research consists of several steps. The first step includes reading each interview several times to organize and sort the data. Significant statements are highlighted. These statements allow the researcher to develop a list of meaning clusters. Each meaning cluster is used to describe the experience and context of the phenomenon. These steps were followed exactly. Creswell (2007) further stated after this process is complete, an invariant structure or essence is revealed in the data, which focuses on the most frequent experiences shared by the participants.

Following Creswell's (2007) steps for phenomenological research, the researcher listened at least once to each audio recording of each interview. The researcher then

transcribed each interview in the exact words of the participant. Next, the researcher implemented the steps outlined and once completed, themes emerged.

Credibility

Implementing a single method of verification will not adequately reveal the interwoven and collective phenomena available. Therefore, to maximize the thoroughness of the method and adequate interpretation of data, triangulation was utilized. Triangulation is a technique used in qualitative studies to maintain and improve credibility. There were several methods to implementing triangulation in this study with collecting data from a demographic questionnaire, recording interviews and taking field notes, and analyzing data with a peer reviewer (Creswell, 2007; Patton, 2002). For the purpose of this study, the researcher utilized a peer reviewer to add validity (Creswell & Miller, 2000).

The peer reviewer was familiar with qualitative research methods and is a doctoral student at Texas Woman's University. Both the researcher and peer reviewer coded the data independently, and then compared our resulting themes from three randomly selected transcripts. The findings were then compared with those of the principal researcher. The peer reviewer also checked biases in the data analysis. She analyzed and coded three transcripts looking for central themes to compare with the researcher's findings. No identifying information was given to her on the three random transcripts that were analyzed. Lastly, the researcher compared her findings with those of the peer reviewer for similar themes and any new themes that emerged. To reconcile

differences, the researcher and reviewer clarified the themes that emerged and determined those that overlapped and were similar (Creswell & Miller, 2000).

Researcher as A Person

One of the principal approaches for improving the accuracy of the results of qualitative research is to clarify the bias of the researcher (Creswell, 2007). Humans have the innate ability to create bias. Therefore, the person of the researcher is an important factor to consider in the research process (Denzin & Lincoln, 2003). One distinctive detail worth noting is that I have been diagnosed with *Alopecia Universalis*. I was diagnosed as an adult, but began losing my hair during early childhood.

Throughout my life, from early childhood to adulthood, my experiences as an alopecian were quite difficult. Not only were they difficult for myself, but having the disease had a huge impact on my family members. At the beginning stages of losing my hair, my mother was accused of not being a conscientious parent. The accusations were not only from family members but from her peers as well. She sought different medical professionals and herbal remedies for a cure, but unfortunately, she didn't find any concrete diagnosis to the problem. Bullying was quite normal during my childhood and adolescent years. However, what is most heartbreaking is that not only was I bullied, but my sister endured countless amounts of pressures from her peers as well.

As I began to mature, I noticed that I was quite shy. I believe the shyness was due to my personal isolation to prevent becoming a subject of bullying. My solace was to delve into books, hide away in libraries, and escape my then reality. As I pushed through

the process into adulthood, I wondered about the potential of a partner and children. To my great delight, I have been married for over 25 years and have 5 children (2 biological and 3 step children). The challenges for my family were just as impactful as they were for me. They had to keep the secret that I was bald. I truly believe my personal isolation and shame of my “true self” was unfortunately projected to my family. My interest in this topic has grown from time to time and I wondered about other people with alopecia areata and what their families may be experiencing. Since all the participants’ family members have been diagnosed with some form of alopecia, it was unknown how the similarities between the researcher and the participants would affect the research.

Subsequently, my belief is that the lived experience of family members is an area worth exploring. Aside from the choice of the research topic, it is unclear in what ways the biases could affect the research. As a researcher, I attempted to proceed without any preconceived ideas regarding the outcome of the research, by setting aside my ideas and reminding myself to listen for the participant’s story only. It is my hope and my intent, as a researcher/participant, to offer new insight into both the medical and family therapy professions, as well as the alopecian community.

Summary

The purpose of this qualitative research was to explore phenomenologically the lived experiences of adult family members of those individuals diagnosed with alopecia. Data were collected from participants who meet the research criteria. The interviews included one open-ended question with follow-up promptings. The audio recorded

interviews were transcribed verbatim and analyzed for any emerging themes. The themes were reported in a narrative format, including excerpts from the participants' responses.

CHAPTER IV

RESULTS

The purpose of this study was to explore the lived experiences of family members of individuals diagnosed with all three autoimmune types of alopecia areata. This chapter reports the results from an analysis of data that were collected from the interviews. The researcher interviewed 15 family members of diagnosed individuals, who volunteered for the study. One participant did not meet the criteria for the study (participant #1A) because the participant was diagnosed with alopecia areata and not a family member; therefore, the participant was not included in the results. The sample for this study was 14 participants. In this chapter, the researcher presents the demographics of the sample, and a narrative of the emerging themes.

Description of Sample

The research sample consisted of 14 family members. The age of the participants ranged from 24 to 68 with a mean of 46. The sample size consisted of 79% female and 21% male family members, representing 10 families. There were two families that had multiple family members participate in the study (Family A and Family F). The researcher conducted 8 face-to face interviews of individuals residing in the North Central Texas area and 6 phone interviews of individuals residing in the states of Illinois (n=1), Ohio (n=4), and Oklahoma (n=1). Two ethnic groups were presented in the sample: African American comprised 21% (n=3) and the remaining 79% (n=11) were Caucasian. Religious affiliations varied: of the participants, 29% (n=4) were Catholic,

21% (n=3) were Christian, 7% (n=1) were Disciples of Christ, and the remaining 43% (n=6) did not disclose an affiliation (Table 1).

The researcher interviewed participants in four states: Texas (n=8), Ohio (n=4), Illinois (n=1), and Oklahoma (n=1). The relationships of the participants consisted of 9 married, 2 engaged, 1 divorced, 1 single, and 1 who did not disclose a marital status. Participants' economic level ranged from \$10,000-\$49,000 (n=4), \$50,000-\$99,000 (n=6), \$150,000 or more (n=1), and others who did not disclose their income status (n=3). There were no participants who reported an income of \$100,000-\$149,000. This sample of participants was highly educated with 2 (14%) doctoral degrees, 2 (14%) juris doctor degrees, 2 (14%) master's degrees, 5 (36%) bachelor's degrees, 1 (7%) associates degree, 1 (7%) high school or GED, and 1 (7%) who did not disclose educational status. No professions overlapped, and included: 1 Retired, 1 Student, 1 Lab Tech, 1 Self-Employed, 1 Graphic Designer, 1 Therapist, 2 Attorneys, 1 Counselor, 1 Teacher, 1 Fitness Instructor, and 2 others did not disclose their occupation (Table 2).

The participants' relationship to a family member with alopecia areata was: 43% (n=6) mothers, 14% (n=2) fathers, 21% (n=3) sisters, 7% (n=1) cousin, 7% (n=1) fiancé, and 7% (n=1) daughter-in-law. The diagnosis of the alopecia areata family member included: 43% (n=6) with alopecia areata, 29% (n=4) alopecia totalis, 21% (n=3) alopecia universalis, and 7% (n=1) did not disclose the diagnosis. Of those family members 57% (n=8) did not receive family therapy, 29% (n=4) received family therapy, 14% (n=2) did not disclose. There were no other family members diagnosed with

alopecia. Over 86% (n=12) were not members of an alopecia areata organization and 14% (n=2) were members of National Alopecia Areata Foundation with one family member also belonging to Children’s Alopecia Project [CAP] (Table 3).

Table 1

Participants’ Study Number, Sex, Age, Race, and Religion

Participant	Age	Gender	Race	Religion
2A	40	Female	African American	Christian
3A	68	Female	African American	N/A
4B	57	Female	Caucasian	Disciples of Christ
5C	48	Female	Caucasian	N/A
6D	34	Female	Caucasian	N/A
7E	33	Female	Caucasian	Catholic
8F	32	Female	Caucasian	Catholic
9F	30	Female	Caucasian	Catholic
10F	N/A	Female	Caucasian	Catholic
11F	65	Male	Caucasian	N/A
12G	29	Female	African American	Christian
13H	53	Male	Caucasian	Christian
14I	24	Male	Caucasian	N/A
15J	57	Female	Caucasian	N/A

Table 2

Participants' Residence, Relationship Status, Income, Education, and Occupation

Participant	Residence	Relationship	Income	Education	Occupation
2A	Texas	Married	\$50,000- \$99,000	Bachelor's	N/A
3A	Texas	N/A	\$10,000- \$49,000	N/A	Retired
4B	Texas	Married	N/A	Master's	N/A
5C	Texas	Married	\$50,000- \$99,000	Associates	Sales
6D	Texas	Engaged	\$50,000- \$99,000	High School or GED	Student
7E	Oklahoma	Divorced	\$50,000- \$99,000	Bachelor's	Lab Tech
8F	Ohio	Married	N/A	Bachelor's	Self- Employed
9F	Ohio	Single	\$10,000- \$49,000	Bachelor's	Graphic Designer
10F	Ohio	Married	\$10,000- \$49,000	Master's	Therapist
11F	Ohio	Married	\$50,000- \$99,000	JD	Attorney
12G	Texas	Married	\$50,000- \$99,000	PhD	Counselor
13H	Texas	Married	\$150,000+	JD	Attorney
14I	Illinois	Engaged	\$10,000- \$49,000	Bachelor's	Teacher
15J	Texas	Married	N/A	PhD	Fitness Instructor

Table 3

Participants' Relationship to Alopecian, Type of Alopecia Areata, Family Therapy, Other Family Members with Alopecia Areata, Member of Alopecia Areata Organization

Participant	Relationship to Alopecian	Type of Alopecia Areata	Family Therapy	Other Family Members	Member of Organization
2A	Sister	Universalis	No	No	No
3A	Mother	Universalis	N/A	No	No
4B	Mother	Areata	No	No	No
5C	Mother	Areata	No	No	No
6D	Mother	Areata	No	No	No
7E	Mother	Areata	No	No	NAAF
8F	Sister	Totalis	No	No	No
9F	Sister	Totalis	Yes	No	No
10F	Mother	Totalis	Yes	No	No
11F	Father	Totalis	No	No	No
12G	Cousin	N/A	Yes	No	No
13H	Father	Universalis	Yes	No	NAAF/CAP
14I	Fiancé	Areata	No	No	No
15J	Daughter-in Law	Areata	N/A	N/A	No

Findings

The purpose of this phenomenological qualitative research was to examine the lived experience of family members of individuals diagnosed with alopecia. To guide this

study, the researcher focused on the following research question: What is the lived experience of family members of individuals diagnosed with alopecia? In qualitative studies, the study is directed by the interview question. The interview question for this study was: Tell me your story. Participants were not limited to the interview question. Each participant was encouraged to speak openly and to elaborate as much as he or she was comfortable. On occasion, prompts and follow up questions were asked to gain clarification on a particular comment made by the participant (Appendix D).

The researcher was able to analyze each participant's narrative by listening to the audio recordings and re-reading transcripts from each interview. After analyzing the data, the researcher was able to identify various significant statements that were grouped into various categories (Creswell, 2007). A peer reviewer analyzed three randomly selected transcripts separately and identified significant statements and themes. When compared, the reviewer's themes were consistent with those identified by the researcher. As participants talked about their experiences with alopecia, three themes and six subthemes emerged: (a) Challenges of Emerging Alopecia Areata with subthemes Seeking a Diagnosis, Experiencing Public Scrutiny, and Is it Stress?; (b) Transitioning to a New Normal with subthemes Choosing Wigs or Not?, Financial Strain, and Supportive Relationships; and lastly (c) Hope for Future Medical Advancements with no subthemes. To support each of the themes, verbatim quotes are used.

Theme One: Challenges of Emerging Alopecia

As the participants began the interview, several responded to the interview question by providing information about the emergence of the disease. Several parents were confused about the onset of the hair loss and each described seeing small smooth patches appearing in their child's head and not knowing what the spot could be.

Seeking a diagnosis. To clarify what the hair loss may be, many parents recalled taking their child to their primary physicians/dermatologist to seek a diagnosis for the reason why the patches were occurring. Unfortunately, many believed the medical professional did not offer much help towards understanding how or why their child was experiencing hair loss. Several stated even though they were left with no concrete answers, the physician would readily prescribe pharmaceutical treatments that were ineffective and had "scary" side effects.

For example, one mother commented on the diagnosis and her feelings about her child taking multiple prescriptions without a valid diagnosis.

Um, there just didn't seem like anything they were doing was making a difference. And we were going through all the difficult treatments the, you know it was the injection they did that for you know a couple of years and then there was other things they did use, um kind of like a folic acid type of treatment? And it was really hard on her! I was just, um you know looking for some answers. I just felt like I was running into a brick wall all the time, even at one point at [local clinic]

they had diagnosed [daughter] with failure to thrive and I, um I struggled with that. (Mother #10F)

Another mother began noticing her daughter was losing her hair while bathing her one evening. She noticed there were small spots on her head and wondered if she was perhaps pulling it out herself. However, she stated one night at dinner she noticed her daughter had rubbed her head and her hands where covered with her hair. After that incident she decided she needed to pursue medical treatment to find an answer.

Well, my daughter was 18 months when she began losing her hair with um some spots in the back of her head. Then sometime later, I noticed she rubbed her head and there was hair on her hands! That was quite scary for me! So, I took her to our primary doctor and he prescribed a medication, but I was concerned about using it. I tried it for a few weeks, but her hair wasn't growing back. So, I asked him if he knew what it [the reason for her hair coming out] was and he couldn't answer. For me, I felt hopeless because how could he prescribe a medication and not know what was causing her hair to fall out? Or, even if it would work? I didn't know what to do! She was so small and I didn't want her to have bad side effects! It just felt awful, not knowing why? It was awful! [tearful] (Mother #7E)

Several other mothers described how scary it was to see their children losing their hair and not knowing what the diagnosis was or how they could help.

Well, it's scary because I didn't know what was causing it, I didn't know what it was, and I knew that her hair had been thinning for a few years. Didn't know what was causing it. (Mother #4B)

But, it is sad as a parent to see your child go through that, you know. [tearful]
How scary it can be to not know how to help your child and not have concrete answers. It was, um just really scary for me because I couldn't help him. (Mother #5C)

I just wanted some kind of answer! I searched online, called other parents, everything! I thought that maybe I could do my own research and find an answer. But nothing. I felt useless, like how could a mom not help their child? It was scary to see my son losing his hair and not help. It was a lonely place to be. I'm supposed to have the answers or find a doctor who could help. And I couldn't do that. [tearful] (Mother #6D)

Two fathers' account of their daughter's hair loss left them feeling helpless and not knowing what to do.

One father described having only one daughter and not being able help her.
Well, she started losing her hair when she was in junior high. At first, I didn't pay much attention because she was so busy with her friends, you know. But, um I remember when her hair started to fall out it was like a big spot at the side of her left or right temple. Then it progressed to around the entire perimeter of her head.

I remember one day, my son came down and said she brushed her hair [long pause, crying] and her brush was full of hair. You know, as a father it's tough to hear that! And there's nothing you can do, but just get to her, and hug her, and try to tell her that it's gonna be alright! [crying] So, me and my wife started getting on line and looking for some type of resources. So we found a doctor and they really didn't know what the cause was. He thought it was alopecia and gave her some medicine. [long pause] Um, it has been a few years now [crying softly] and she has lost all of her hair. Now, what can be done? Will it return? How can I help my little girl? You know. Dads are there to protect their little girls, and I can't. It hurts, you know. I just feel helpless at times. Like, um I can't save my baby girl! Not from this. [whispering] (Father #13H)

Another father stated:

My wife is the one who does all of the medical care for the girls, because I travel a lot. So, when she began to get worried about it she started talking to me. I didn't want to make a big deal about it because I didn't want to hurt her feelings. [long pause] But, um she [daughter] just started getting very sad. She wouldn't go out much and stayed in her room. I knew that it was because of her hair and I couldn't help her. [pause, voice lowers] She had all these patches on her head and it looked like she had cancer. I didn't know how to help her. I didn't know what to say to her. I didn't know. Dads solve problems. That's what I do. There was nothing we

could do to stop the hair from falling out. Her mother couldn't find any help with the doctors' and she was very sad about that. How could I help my daughter? I just couldn't and that hurts me deeply. (Father #11F)

Experiencing public scrutiny. As the family members recalled the past and the onset of the disease, they also remember how others would stare at their family member in public settings. Several felt that those individuals who stared were looking at them critically and not turning away. The family members believed that those staring thought that their loved one had cancer, or were wondering what could be the cause for their hair loss.

A mother could recall taking her son with her to the grocery store and began her usual shopping for meals. As she walked down the aisle, her son was inside the shopping basket playing a small electronic game. While walking on one aisle she noticed a lady staring at her son and her son quickly shrugging his shoulders and slouching into the basket, as if trying to hide himself from the uncomfortable stares.

I can remember it vividly, we were walking down this aisle and there was a lady STARING at him! I mean, she didn't politely glance, she was blatantly staring! People would watch him when we go to the grocery store. Parents looking at you like you've done something wrong to your child. [tearful] I think maybe I'm a little bit more sensitive to that kind of thing. It was just hard to see that people would make us feel uncomfortable. It's just heartbreaking, um to see your child feeling ashamed for something he didn't do. [tearful] (Mother #5C)

A sister recalls one evening when the family was out to dinner and the people at the other table were staring at her sibling. She remembers feeling uncomfortable and helpless and did not know if she should make a comment or stay silent.

So, um I remember people just staring at her and people would wonder if she would have cancer or anything like that. But, um they didn't know what alopecia is. So, um it was nothing that I would be able to deal with, um you know what [sister] went through. Because it was difficult watching people looking at her and they really didn't have a filter. [pause] Well, it was like that they didn't care if they saw us staring at her. It didn't really seem like it mattered to them. Or they wouldn't hide the fact that they were like staring at her and wondering what was wrong. That was hard for me and my family. Very hard. [took a deep breath]
(Sister #9F)

An additional family member recalled her cousin being stared at consistently when they were young and remembered her isolating herself from others. Later in life, she recalled that her cousin began to outwardly adorn herself to diminish the stares from others.

It was hard growing up with that [watching others stare] and watching her NOT desire to play outside or just be a little girl, you know....I worry a lot, um if she will ever be comfortable around other people! It hurts to watch her not be comfortable. You know? (Cousin #12G)

A father spoke about his daughter and how others stare at her wondering if she has cancer. He expresses the difficulty of watching his daughter having those experiences in different settings.

Then I remember she was playing soccer at that time and I was trying to protect her from others staring at her. I remember being at soccer game and trying to explain to people that she was okay. You know. [crying, long pause] They see her and stare and think its cancer. Everybody think she has cancer or something like that because she doesn't have any hair. It's just hard to see others staring and it increases the anxiety of watching your child, you know, go through this. She's feeling embarrassed and trying to be normal. But other people are staring and asking questions. It just hurts. [crying] (Father #13H)

A fiancé spoke about the desire to protect the woman he loves from her feeling like everyone is staring at her. He expressed the difficulty he feels to help her become comfortable with who she truly is.

One day I noticed others staring, but I also noticed her choosing to not really go anywhere. Well, you know it's hard for me when I see her or shall I say hear her talk to me about what she thinks others will feel when they see her without her hair piece. I think it's hard for me because I really want to protect her and I feel like she can walk outside as her true self and not really care. And I think, um one day she will be able to do that and she will be able to go out and really be her true

um self. But I know she's not ready for it yet. That's hard when I see her as a beautiful person and she doesn't. Having others stare and she just, um chooses to stay inside. Um, it truly hurts me. (Fiancé #14I)

Is it stress? Each family member reflected upon the difficulty of disease from the onset of the hair loss to seeking medical solutions. Yet, many wondered if the stressors they observed their loved one experiencing were the cause of the hair loss or if both were interrelated.

I just assumed it would come back. After her period of stress or whatever her stress level was. Rather it be her marriage, her kids, her work. I just assumed that it would come back. I just couldn't put my finger on it. (Sister #2A)

She was working on her master's and then she went to [another country] for a week and she came back from [another country] and didn't adjust to the time and then had to go back to work. So, she had sorta like, a little break down. So after that, I can't link the two before, but I've always wondered about that. Because after that, that's when she started losing her hair. (Mother #3A)

I think she did, um she was upset, she was studying really hard, she was getting ready to take her licensure exam for the counseling license, and you know. We

just thought that it was a lot of stress and things were just crazy for her. (Mother #4B)

I just noticed that my son started wondering about college and was beginning to study for his college entrance exams. He was under A LOT of stress at that time! I remember him not sleeping and worrying if others would know that he had alopecia. That's when it started falling out again. Later, in college he wanted to rush for a fraternity and he called because he noticed his head was getting spots. He was so sad! He was worrying about shaving his head and the other guys noticing the spots on his scalp. It's sad to hear your son is off to college and he still is having problems with his hair loss. That just really, um was tough for me! [tearful] (Mother #5C)

I noticed my when my son starting losing his hair that my husband and I were going through a divorce. I think he was under a lot of stress because we were trying to figure out the custody issues. He would constantly ask about his dad when we moved into our own place. He was really worried. (Mother #6D)

I do notice that when she is stressing out, that her hair starts to fall out. I try everything to keep her from stressing and help her to calm herself. Like, one time she was on her new swing and it was a little scary to her. She was very afraid and

started crying. So, I took her off, but later I noticed her hair was shedding that night. I try to do everything I can for her not to stress. I just don't want her to lose all of her hair! (Mother #7E)

So, I started wondering if that's why she lost her hair at that time. She was probably under a lot of stress. I didn't know about the alopecia at that time. But I do know that it was a very stressful time for her and her family. (Cousin #12G)

Um, I know that my mother-in-law really started losing hair in her mid fifties, when she was having medical problems. I remember her stressing about having surgery and being afraid about it. We would try to help calm her, but it didn't really work. That's when I noticed her hair was thinning even more! So much so that she started wearing a hat to cover her head. No matter what I tried to do to help ease her stress, she just would not let me help her. Um, that was hard for me to watch her. It's still a little upsetting for me. (Daughter-in-law #15J)

Theme Two: Transitioning to a New Normal

The family members reflected about the onset of hair loss and the stressors that may have been interrelated with the loss. Many began to respond to times when their loved one began developing strategies towards coping with the disease and accepting their present condition. One way in which their family member began coping was they ceasing medical treatments and pursuing alternative solutions.

Choosing wig or not. The family members reflected on their loved ones' choices to wear wigs, head coverings, or nothing at all. Each expressed a sense of joy and relief about their choices. A few mothers discussed the time when their daughters chose to wear wigs. Each believed it was a great choice and was amazed at the change they made after their decision.

One mother discussed when her daughter started wearing wigs in high school. She was relieved by her daughter's choice because she noticed the transition was pretty smooth for her.

Yeah! And we saw that when she got the wig no one ever really bullied her. But by the time, um she got to high school. It went pretty smoothly, um but by that time she was wearing a wig every day. And I'm glad that she made that choice.
(Mother #10F)

This mother spoke about her daughter's choice to wear a wig. She believed her daughter is happier.

Um, she was working for [local company] and she was able to go to this place where celebrities go and get wigs and stuff. Right. So, she adjusted to that and she has been comfortable with hers. And I like that! I like that she did get wigs because she seems happier. (Mother #3A)

Another mother described her daughter's choice to cut her hair into a different hair style. However, if she does have a need to wear wigs in the future, she would do so with confidence.

And you know she said, "I'll be a rocking bald girl! I can have wigs! I can look different everyday! If, I want to!" [laughing] I mean, she just had this whole thing! I mean, that's my greatest hope is that she will absolutely feel that way.
(Mother #4B)

A few sisters described their siblings' choice to chose to wear a wig and how each person thrived with the new wigs. They recalled watching their siblings flourishing and the excitement they felt as well as observing their sibling's new change.

And so, she decided to wear a wig. And, you know whenever she decided that she was okay with it....And um, she does well. She changes her wigs out. She maintains the look that she had when she was getting her hair done....And I'm happy with that. (Sister #2A)

I remember my sister starting to wear her wig. Honestly, I felt like I had my sister back! She was hanging out with friends, going out, and everything during high school. I'm pleased that she started wearing them. (Sister #8F)

But I think that was about the time they started looking for wigs and that's when about that time she actually got her first wig..... And in high school she flourished! And high school, I mean she or I'm not really sure what made her change maybe it was getting the wig that kind of changed things for her. In high school she had tons of friends and she still talks to her friends now. You know, looking back that's when she really started being open to us as well. I really enjoyed watching her becoming a new person with her wig! I loved it! (Sister #9F)

Other loved ones recalled when their family member started the journey towards wearing wigs and the positive change it was for them as well.

But I think it was around high school? I believe? It's when she started wearing her wigs. What a change she made! She blossomed into a new person! We didn't see an angry person anymore. My cousin was back. Thank God! I remember how happy she was and we all were just, thankful and grateful that she had something that made her feel normal. [smiling] (Cousin #12G)

Um yes, she told me that she was thinking about, um you no shaving her head and getting a wig. She hadn't felt the confidence to do so. To do, you know such a bold move. And about 3 months into us dating, um she did it! She went to a salon that she liked and she got her head shaved and she found a wig that she liked. It was hard for her....She's been wearing one ever since. But I'm so proud of her

choice! I'm really, proud of her and it makes me love her even more! (Fiancé #14I)

After her hair began to thin and it was noticeable that she didn't have much hair, she started wearing wigs. She didn't really like them because they were very hot and itchy. So she started crocheting hats for the winter! I mean she is really good at it. She also started finding these really cool hats! They are comfortable to her and she feels like she is wearing a style she would wear from her home land. I really, really love that she has found something that makes her comfortable! And she looks great in them! [smiling] (Daughter-in-law #15J)

Financial strain. Two fathers were elated about their daughters' desire to wear a wig and accepting the hair loss. Yet, they both wondered about the lack of support they received from their insurance carriers. Each expressed the financial cost was quite expensive and the need to have insurance institutions reimburse a least a portion of the cost.

It just seems awkwardly unfair that insurance companies don't recognize this as a disorder. Um, you think that it would be important to know that or to wear a wig is something that would be necessary for people. You know, that puts a strain on the budget sometimes. Um, you know to buy a wig every year....I believe part of the problem is the insurance does not want to help pay for the hair or the wigs that

people with alopecia need. I'm not sure if it's because of the time frame that they have to wear the wig or how they can compare allocations to cancer patients, it just seems unfair. (Father #11F)

You know, we have to search for her wigs to find a reasonable price that looks nice. It sometimes gets frustrating that the insurance companies don't want to help pay for them! They support medications that don't work but not the wig cost. I can't let my daughter wear a wig that makes her look bad and the insurance companies do not want to reimburse for them. It's just frustrating. We are still waiting on an appeal that we had to file for reimbursing the cost for her wig. They can get expensive and it seems like they really don't care about the needs of people with alopecia. (Father #13H)

Supportive relationships. A vital part of transitioning into accepting the present was that the person with alopecia began telling their close intimate friends and others about the disease. Telling others about their hair loss was often freeing and allowed them to see themselves as normal or offer others a reason why they didn't have hair. Many of the family members believed once their loved one shared about the hair loss that they had developed an essential support system.

This sister discussed how the family supported their loved one. They believed it was important to understand that she had adjusted and accepted that she didn't have hair and decided to continue her journey for herself and her children.

I guess this is what we will have to deal with. Or I mean she has to deal with it.

And like I said, everyone was supportive for her and the kids. (Sister #2A)

A mother described the importance of supporting her daughter after her daughter had accepted herself without hair. She realized it made a difference in her to see her daughter was empowered.

And when you do have someone to support you she, she feels like, um what she feels is empowered that we do help her and support her change in accepting herself with alopecia. If feels good. [smiling and tearful] (Mother #4B)

This mother spoke to a school teacher and the principal about her son's hair loss. She wanted to clarify the reason for him wearing a hat to school. It was at the beginning of his hair loss and he felt uncomfortable in the classroom without his hat. The school teacher did not support him wearing the hat, until the mother received permission from the school principal. Having the support made a change in the classroom setting when all the children in his class wore hats.

I had to talk with his teacher and the principal about his hair loss. They allowed the other kids to wear a hat in class and it made him feel like he wasn't the only

one wearing one? Does that make since? Not only did the principal support him, the other kids and parents really rallied around my son to support him! [tearful] Um, that meant a lot to me. To know the school community supported him. [voice lowering] (Mother #6D)

This family included the parents and two sisters of the person diagnosed with alopecia. Each family member supported their loved one, strengthening the family bond.

Our family realized that we accepted [sister] and that our love would never change. But the support came from others also, like our extended family members. Going to family functions she was herself because she knew that we loved her. [deep breath] Um, she's our family. You know. [tearful] (Sister #8F)

This has really been an eye opening experience and I think it has been really therapeutic for her and for me and my older sister and she has really opened up and talk to us about it just recently. Just talking with us about her experiences has helped us to understand her. I hate that she or even we waited this long to talk about her feelings. But it also feels good that she can share with us and we can truly understand her. It's bonded us together and allowed us to be a supportive family for her. It's like it's not hidden? You know. [chuckling] (Sister #9F)

And also our extended family has been very supportive and I'm very appreciative how they just really just rallied around her. I think that's what definitely carries her to, um is to have supportive family members not only in our home but our extended family. (Mother #10F)

You know that, that, I think that helps. I think the fact that she's got support from her sisters and they've kinda embrace the whole issue. It is a positive for her and for our family. And I um, am thankful, um that we have got a lot of support from our immediate family and from our extended family. (Father #11F)

A cousin spoke about her cousin having not only her family support, but having supportive friends that were there for her.

And then of course there were those one or two girls that were really trying to be friends and trying to be there for her. It was refreshing to know that not only was the family there for her, but she also had friends. (Cousin #12G)

A fiancé spoke about his family supporting his loved one and accepting her. He was impressed that she revealed to his family that she had alopecia.

Or you know, um to know what it was like for her and to see her and not be able to do anything but be very supportive not only myself but also my family.

Especially, um when it comes to her being around my family. Which, um they are

totally understanding, um but it took her awhile to, um I guess “come out” if you will. (Fiancé #14I)

Theme Three: Hope for Future Medical Advancements

As the family members reflected about hair loss and the treatment processes their loved ones encountered, several had concerns about the effectiveness of the treatments. Some decided to cease medications for their children due to the side effects and long term use. Others wondered if the medical field could gain a better understanding towards a proper diagnosis during treatment or even if there could be research to find a cure.

I hope they can find something out about why this has happened. You know. Something to help the doctor's and we don't have to have a lot of misdiagnosis. (Mother #4B)

I just keep hoping that the medicine will work or for it to get better or that he [doctor] can have a better understanding or that they'll have a cure or just figure out what's causing it. (Mother #5C)

I just wonder if they can find a cure, or if they can find other medications that are safe for your child? The side effects are scary and I'm concerned about those children who take them and not know what may happen in the future. They don't have enough research about it. (Mother #7E)

I mean, kind of like long term [alopecia] and there's not really a cure for it or how to fix it emotionally. I just hope there is something that can be done. (Mother #9F)

You would think, like looking at male pattern baldness that they certainly came up with, or um some sort of a cure to assist with the hair loss. I just hope they can find a cure in the future. (Father #11F)

You know, we chose to stop our daughter from taking the medication because the warning on the prescription stated pregnant women could not take it! I do not want to make a decision for her that could cause her to not have children later. If, she decides later in life she wants to take it, I'll pay whatever it costs. But not now. Not now. Honestly, there should be more research and medical physicians understanding the risk. Especially, considering the long term effects. There's not enough knowledge about it. (Father #13H)

Summary

This chapter presented the results of a phenomenological research study that explored the lived experiences of family members of individuals diagnosed with alopecia. The study included 14 participants and represented 10 families. The participants for this study resided in several different states. A research assistant reviewed several transcripts as a means to triangulate the data and help with the credibility of this research. The demographic characteristics of the sample, three emergent themes and subthemes, and

verbatim quotes of the participants to illustrate the themes were presented in this chapter. The analysis of the interviews identified three themes and six subthemes: (a) Challenges of Emerging Alopecia Areata with subthemes Seeking a Diagnosis, Experiencing Public Scrutiny, and Is it Stress?; (b) Transitioning to a New Normal with subthemes Choosing Wigs or Not?, Financial Strain, and Supportive Relationships; and lastly (c) Hope for Future Medical Advancements with no subthemes. Each of these themes, along with several of the participants' comments, was included in this chapter.

CHAPTER V
DISCUSSION, CONCLUSIONS, LIMITATIONS AND
RECOMMENDATIONS AND IMPLICATIONS

The purpose of this qualitative study was to examine the lived experiences of family members of those individuals diagnosed with alopecia areata. Systems theory was used as a lens through which these family members' experiences were reviewed and a phenomenological approach allowed the researcher to discover each individual's unique meaning surrounding their lived experiences. Semi-structured interviews were conducted with the individuals who agreed to participate in the research. This chapter covers a discussion of the findings and the conclusions. Also, included are the limitations of the study, clinical implications, and recommendations for future research.

Discussion of Findings

As the research data were analyzed, three themes and six subthemes emerged. Each theme was apparent in the responses to the interview question: Tell me your story.

The following themes and subthemes emerged from the transcripts of the 14 interviews:

- Theme One: Challenges of Emerging Alopecia Areata
 - Seeking a Diagnosis
 - Experiencing Public Scrutiny
 - Is it Stress?
- Theme Two: Transitioning to a New Normal
 - Choosing Wigs or Not?
 - Financial Strain
 - Supportive Relationships
- Theme Three: Hope for Future Medical Advancements

The first theme, *Challenges of Emerging Alopecia Areata*, directly reflected the participants' response to recalling the onset of the disease and the challenges they faced to understand its cause. Gaining knowledge about the disease became difficult for the participants as they sought answers from their medical professionals. Earlier autoimmune studies also reported individuals experiencing hair loss felt isolated due to the limited knowledge of medical professionals (Hodgson, et al., 2004; Hunt & McHale, 2005a, 2005b; Tucker, 2009).

Family members recalled a sense of social isolation due to others staring and they speculated about the limited knowledge about the disease in social settings. Bacigalupe & Plocha's (2015) study agreed that family members experienced isolation due to the lack of knowledge about a disease that is not socially recognized.

Several participants wondered about the onset of the disease and questioned if alopecia areata could be linked to different emotional or psychological stressors their family member had experienced. Earlier studies support that psychological stress could be factors for hair loss (Hunt & McHale, 2005a, 2005b; Tucker, 2009; Mayo Clinic, 2016b).

Theme two, *Transitioning to a New Normal* entailed the family members expressing a myriad of emotions as they recognized their loved one transitioning towards accepting the condition. Many participants remembered their family member ceasing the use of medications and choosing to wear wigs due to hair loss. Each told different stories about their loved one's choices and how pleased they were with the decision to choose to wear

wigs or not. Lastly, maintaining supportive relationships allowed the family to cope with the condition.

Studies have shown individuals choosing a different alternative after experiencing excessive hair loss may be a good choice (Mayo Clinic Staff, 2011). Although accepting another option for their hair loss was a positive choice, some family members said that the decision to buy a wig was a financial strain without the aid of insurance reimbursement.

Most believed that supporting their family member was essential to their loved one's ability to cope with the disease. The studies of Colón et al. (1991), Helgeson et al., (2003), Hodgson et al. (2004), Hunt & McHale, (2005a, 2005b) and Bacigalupe and Plocha (2015) all reported that encouraging positive relationships with friends and family was essential for the well-being of alopecia areata patients. The family member believed maintaining supportive relationships was important because it helped them manage stressful moments.

The final theme, *Hope for Future Medical Advancements*, focused on the participants' concerns about the effectiveness of medical treatments for alopecia areata. Many parents were worried about the impact of the treatments that had long term side effects. They wondered if the medical field could gain a better understanding about the disease, initiating proper diagnosis, and/or researching more to gain knowledge towards finding a cure. National Alopecia Areata Foundation (2016) and other research

institutions such as the Mayo Clinic (2016a) agree with the participants and have enacted research studies to both find a cure and create new knowledge about the disease.

The Researcher's Voice

As the researcher in this qualitative study, I am not only a student in a Family Therapy doctoral program, but have myself been diagnosed with alopecia universalis. I believe an important factor in this study is the voice of the researcher and to not allow my voice to be heard would be a disservice to this study. Therefore, I will attempt to describe the effects this study has had on me.

My curiosity about family members' experiences began to increase after the death of my mother in 2010. I remember feeling a sense of loss and bewilderment for not knowing her journey as a mother with a child who has alopecia universalis. Within my family system, my hair loss was not discussed, but remained as an "elephant in the room." I can recall the journey my mother took when I was a small child to find a cure or some type of resolution to why my hair was falling out. With no concrete answers she stopped her search. However, during my latter childhood, she sought different medical professionals, hoping there was more knowledge about my hair loss. Yet, to her dismay she never received a definite diagnosis or reason that my hair would not regrow. Her next pursuit was to try different herbal treatments, which she would apply to my head ritualistically. Unfortunately, those remedies were ineffective also.

During that entire process I wore a scarf to cover my head. Wearing a scarf was difficult for me because I became a target for bullying. Being different was not easy for

me. I would run home after school to prevent other children from pulling off my scarf and teasing “the bald girl.” They would pull at my scarf in class, on the playground, and sometimes on the school bus. I remember countless times calling her from school crying because the other students were relentless with their bullying.

The last process my mother chose was for me to wear a wig. The change was not any better. The children would continue their bullying, mostly because the wig I wore was an adult wig. I can remember it was huge and we would try to alter it, but it still looked abnormal on a small child’s head. During that time (early 1970s) the impact of bullying was not as well known. To prevent other students from teasing, some teachers would either allow me to remain in their classrooms or let me go to the library to read. The library became my solace throughout my educational journey as a child and through my adolescent years. I often wondered how my hair loss affected my mother.

Interestingly, not only was I bullied, but my younger sister was also. Other students would refer to her as “the girl with the bald sister.” From early childhood to the present, she has rarely discussed her experiences and states she chooses not to. Again, “the elephant in the room,” no one in our family chose to talk about my hair loss. Not even me. After my mother’s death, I attempted to ask my sister again and she continued to state she is not interested in discussing her experiences. No one discussed my hair loss, not my mother, sister, husband, children, or me. I wondered if the “family secret” was carried systemically into my nuclear family. Were my spouse and children afraid to tell the secret that I was bald? During my studies at Texas Woman’s University, I often

wondered as a family therapy student and professional, “Were other families discussing alopecia areata with their loved ones?” or “What was it like for others diagnosed with alopecia?”

In describing my position with this study, it was difficult for me to separate myself because I could identify with the participants’ family members as being a person diagnosed with alopecia universalis. As well as one can, I made every effort to suspend my biases and assumptions while conducting the interviews and analyzing the data. Also, I listened to each family member’s story with no preconceived ideas or assumptions, while understanding that individuals make meanings from their own personal experiences.

After speaking with my advisor, I believed it was important for me to disclose that I was diagnosed with alopecia universalis. I do not know if any participants treated me differently because I am alopecian. As I began the process of interviewing participants, there were a few who admitted they were more open to discussing their experiences with me because I was alopecian. Interestingly, during the interview process a few made comments like, “I’m sure you understand what it’s like!” or “Well, you don’t have any hair that must be hard!” At the end of most interviews, many were quite thankful that someone could hear their story. They expressed that they had never spoken to anyone about their family member who had alopecia areata and was relieved that someone would listen.

A surprise for me during this study was how I began to recall my past experiences. As mentioned earlier, our family never spoke about my hair loss. As the participants shared their stories, my story came alive and I sought therapy to deal with the feelings coming up for me. The counseling sessions helped me to realize that not only was I experiencing pain, I was accepting who I was, a person with alopecia. I had not realized that I was “hiding in the closet” and afraid for others to know that I was bald. This research has allowed me to see “my true self.” I have come out of the closet and have taken steps towards sharing with others about my hair loss. The journey of this study has empowered me not to be ashamed. The participants’ stories about supportive relationships and their united strengths were the catalyst for me to gain my own power and self-worth. My hope is that those individuals diagnosed with alopecia areata will gain a sense of true identity as they read the stories of the participants. Secondly, my hope is that others will discuss their family members’ hair loss and not be ashamed. Lastly, I hope that both the marriage and family therapist and medical professionals will become educated about alopecia areata and offer much needed help to the family system.

Conclusions

The findings of this research provided possible answers to the research question: What is the lived experience of family members of individuals diagnosed with alopecia areata? Based on the findings of this research, the following conclusions are provided. Family members desired better knowledge about alopecia areata in the medical professions. They discussed medical visits that did not offer a clear answer to the

problem about their loved ones hair loss. They believed the medical treatments offered were ineffective and was unclear about the long term side effects and hoped their medical physicians could have better knowledge about medications offered for treatment. Also, family members hoped the medical fields could offer further medical research to seek a cure for alopecia areata.

Family members discussed keeping a positive support system helped them to cope with the condition both socially and personally. They felt socially isolated due to the lack of knowledge about the condition in social settings. With some wondering about the onset of the condition and questioned if alopecia areata could be linked to different emotional or psychological stressors their family member experienced. Fathers discussed a need for assistance from insurance companies to reimburse the cost of wigs because of the high cost for quality wigs and the potential for a long term need. Lastly, family members believed maintaining supportive relationships were important because it helped them manage stressful moments.

Limitations and Recommendations

Several factors limit the generalizability of the conclusions of the study. The sample of the participants was not randomly selected. Because the study focused on a sensitive topic, some family members, no doubt, chose to not participate. Due to a small number of individuals participating in the study, caution should be used in generalizing to a larger population. With the exception of two individuals, the sample consisted of family members having college degrees and more than half having graduate degrees. A sample

with less education might have described different experiences. In any study that relies on retrospective data, it may be assumed that the present may have an influence on one's memory of the past.

In addition, with the exception of Family A and F, only one family member's perspective was heard, which is a potential overrepresentation of themes from multiple family members from one family. Participants may have refrained from responses that are more critical in an effort to not insult the researcher. Participants' family members diagnosed with alopecia areata had a developmental range that included ages from early childhood to adulthood. Each family member discussed their experiences based on different developmental stages. Therefore, the time of the diagnosis could vary the participants' responses about their experience. Finally, this phenomenological study was designed to be descriptive only of these family members' experiences, rather than to be widely generalizable or predictive.

This study added to the body of literature that examines the lived experiences of family members of those diagnosed with alopecia. However, more research is needed to broaden the field and better inform professionals who may work with family members of those diagnosed with the disease. The following are recommendations for future research. This study could be replicated to include other racial, ethnic, religious, socioeconomic and educational backgrounds. Research that examines the participants across time to verify if their experiences change after the family member has been diagnosed through

several stages of the lifespan. Researchers should examine extended family members and others who offer a supportive relationship to the family unit.

The couple system should be examined to identify the impact of alopecia areata within the couple. The fathers' stories added another prospective to the parental subsystem and should be investigated for better knowledge as to how they are impacted by alopecia areata. Therefore, due to limited number of fathers participating in the study, fathers of those diagnosed with alopecia areata should be explored. Lastly, siblings of those diagnosed with alopecia areata should be examined to understand the impact of the disease on the sibling relationship.

Clinical Implications

The results of this study highlight the importance of recognizing that using a systemic perspective is important when working with this group of people. Families are impacted by any disease when a loved one has been diagnosed. Therefore, when working with an individual, marriage and family therapists must understand that many individuals are a part of a family system and a systemic lens must be implemented. Marriage and family therapists should encourage families to maintain a supportive relationship that aids them in coping with the disease. Since the onset of alopecia areata could occur at any age from early childhood, youth, adult, and later life, marriage and family therapists should be aware of these developmental stages and how the disease can impact each stage differently. Lastly, due to the sudden onset of alopecia areata and many family members feeling isolated and unclear about their loved one's future, it is important for marriage

and family therapists to provide grief support. Grief support will aid the family member with accepting the loss of hair and developing a better understanding of alopecia areata.

Summary

This study explored the lived experiences of family members of those diagnosed with alopecia areata. The general systems theory was used as a lens through which these families' experiences could be seen, and a phenomenological approach allowed the researcher to understand the meaning alopecia areata has in their lives. From the data analyzed, a discussion was provided for the three themes and six subthemes that emerged. The findings for this study have implications for marriage and family therapists and medical professionals. Recommendations were made for future research. These research data offered a broader understanding of the systemic effects of alopecia areata upon the family unit.

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APPENDIX A
Recruitment Flyer

HAS SOMEONE IN YOUR FAMILY BEEN DIAGNOSED WITH ALOPECIA AREATA, TOTALIS OR UNIVERSALIS?

If so, and you are 18 or over, I'd like to hear your story of this experience!

I'm **Barbara Buchanan**, a doctoral student at Texas Woman's University conducting voluntary confidential interviews to explore the experiences of family members of persons diagnosed with Alopecia. The interview will take about an hour at a safe and agreed upon location between the researcher and participant. It's my hope that the results of this study will aid family therapists and other professionals to better help those living with Alopecia, as well as their families.

May I tell you more about this research?

Please phone me at (xxx) XXX-XXXX or email [*contact information deleted*].

If you know of others who may be interested in this study, please pass along my contact information.

My research advisor can be reached at (940) 898-2713 or LBrock@mail.twu.edu.

As with any electronic submission, there is a potential risk of loss of confidentiality in all email, downloading, and internet transactions. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the TWU's Institutional Review Board at 940-898-3378 or via e-mail at IRB@twu.edu.

APPENDIX B

Consent to Participate in Research

TEXAS WOMAN'S UNIVERSITY
CONSENT TO PARTICIPATE IN RESEARCH

Title: The Lived Experiences of Persons Diagnosed with Alopecia: The Effects on Family Members

Investigator: Barbara Buchanan, B.S., M.ED.....BBuchanan1@mail.twu.edu
(817)

Advisor: Linda J. Brock, Ph.D.....LBrock@mail.twu.edu
(940) 898- 2713

Explanation and Purpose of the Research

You are being asked to participate in the dissertation research study conducted by Barbara A. Buchanan, B.S., M.Ed. at Texas Woman's University in Denton, Texas. The purpose of this study will be to explore the lived experiences of family members of individuals diagnosed with alopecia.

Research Procedures

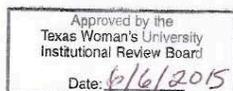
For the purpose of this qualitative study, the principal investigator will conduct face-to-face individual interviews with each family member who agrees to participate. This interview will be scheduled at a time and location that is safe and mutually agreed upon by you and the researcher. The interview will be digitally audio recorded for later transcription and data analysis to provide accuracy in reporting the information discussed. The PI, advisor and additional research team member will also have access to the transcripts. The maximum time commitment for the interview is approximately 1 hour. Your interview will be transcribed and assigned a confidential code.

Potential Risks

Potential risks related to your participation in the study may include fatigue during the interview. To avoid fatigue, you may take a break (or breaks) during the interview as needed. Another potential risk may include emotional discomfort. If you experience emotional discomfort regarding the interview questions, you may stop answering any of the questions at any time. The investigator will provide you with a referral list of names and phone numbers that you may use if you want to discuss this discomfort with a mental health professional. The referral resources include the Therapist Locator for American Association for Marriage and Family Therapy (AAMFT) www.aamft.org/therapistlocator/ and the Counseling and Family Therapy Clinic at Texas Woman's University, Human Development Bldg, Room 114, Denton, Texas 76201 (940) 898-2600.

Another possible risk to you because of your participation in this study is release of confidential information. Confidentiality will be protected to the extent that is allowed by law. The interview will take place in a private location agreed upon by you and the researcher. A code number, rather than your name, will be used on the audiotape and transcription. Only the investigator and her advisor will have access to the recordings. The flash drive, hard copies of the transcriptions, and the thumb drives containing the transcription text files will be stored in a locked filing cabinet in the investigator's locked office. The recordings and typed transcription will be erased and the hard copies of the transcriptions will be shredded within 2 years of the completion of the study. It is anticipated that the results of this study will be published in the investigator's dissertation as well as in other research publications. However, no names will be included in any publication.

Participant's initials Page 1 of 2



The researcher will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

Participation and Benefit

Your participation in this study is completely voluntary and confidential and you may discontinue your participation in the study at any time without penalty. The only direct benefit of this study to you as a participant is that at the completion of the study you may request a summary of the results to be mailed to you.

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have questions about the research study you may contact the researcher or advisor. Their contact information is provided at the top of this form. If you have questions about your rights as a participant in this research or in the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at (940) 898-3378 or via email at IRB@twu.edu.

Signature of Participant

Date

* As with any electronic submission, there is a potential risk of loss of confidentiality in all email, downloading, and internet transactions. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the TWU's Institutional Review Board at 940-898-3378 or via e-mail at IRB@twu.edu.

* If you would like to receive a summary of the results of this study, please provide an address to which this summary may be sent.

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Approved by the
Texas Woman's University
Institutional Review Board
Date: 6/6/2015

APPENDIX C
Demographic Information

DEMOGRAPHIC INFORMATION

DATE OF INTERVIEW: _____ **PARTICIPANT CODE:** _____ **AGE:** _____

FEMALE: _____ **MALE:** _____ **OCCUPATION:** _____

RACE/ETHNICITY:

- American Indian or Alaskan Native
- Asian
- African American
- Caucasian
- Hispanic
- Native Hawaiian or Other Pacific Islander
- Other (please explain): _____

STATE YOU RESIDE IN: _____ **RELIGIOUS/SPIRITUAL**

AFFILIATION: _____

RELATIONSHIP STATUS: Married _____ Single _____ Divorced _____ Widowed _____

Other _____

NUMBER OF CHILDREN: _____ **CHILDREN'S AGES:** _____ , _____ , _____ ,
_____ , _____

EDUCATION LEVEL:

- High school diploma or GED
- Associate degree (for example: AA, AS)
- Bachelor's degree (for example: BA, AB, BS)
- Master's degree (for example: MA, MS, MEng, MEd, MSW, MBA)
- Professional degree (for example: MD, DDS, DVM, LLB, JD)
- Doctorate degree (for example: PhD, PsyD, EdD)

ANNUAL GROSS INCOME:

- I earn less than \$10,000
- I earn between \$10,000 and \$49,999
- I earn between \$50,000 and \$99,999
- I earn between \$100,000 and \$149,999
- I earn \$150,000 or more
- Other (i.e unemployed, student, etc.)

ARE YOU A MEMBER OF AN ALOPECIA AREATA ORGANIZATION? (i.e. National Alopecia Areata Foundation [NAAF], Children's Alopecia Project [CAP])

YES _____ NO _____ If Yes, which one? _____

WHAT TYPE OF ALOPECIA DOES YOUR FAMILY MEMBER HAVE? _____

WHAT IS YOUR RELATIONSHIP TO THE PERSON WHO HAS ALOPECIA AREATA? _____

WHEN DID THE FAMILY MEMBER'S HAIR BEGIN FALLING OUT? _____

WHEN DID YOUR FAMILY MEMBER FIRST HAVE HAIR LOSS? _____

ARE THERE ANY OTHER FAMILY MEMEBERS WITH ALOPECIA AREATA? _____ IF SO, RELATIONSHIP TO YOU? _____

HAVE YOU OR ANYONE IN YOUR FAMILY GONE FOR COUNSELING OR THERAPY? IF YES, WHO WENT AND HOW HELPFUL WAS IT? _____

APPENDIX D
Interview Protocol

Interview Protocol

Participant's Code: _____

Date of Interview: _____

“Thank you for agreeing to participate in this study. As we discussed, the purpose of this research is to explore the lived experience of family members of individuals diagnosed with alopecia. Do you have any questions?”

“Before we begin the interview, let's go over the consent form.” “Do you have any questions about the consent form? After you sign the form, I will give you a copy to keep.”

“The question I ask you during this interview will be centered on your experience of alopecia areata in your family. During the interview, I will be taking some notes. Any names used in our interview, including yours, will not be used when I transcribe the recording. Only your code number will be used.” “Do you have any questions before we begin?”

“Ok. I am going to turn on the recorder now. As a family member of a person diagnosed with Alopecia, please tell me your experiences.” So, my interview question is: Tell me your story. (Pause to hear response and use prompts as needed.). At the end of the interview, the researcher will ask: “Anything you'd like to add? Thank you very much for sharing your story.”

Prompts:

What happened?

Nodding

How?

I see

How did you manage that?

Silence

What effect did that have?

Who else knew?

Did you tell anyone?

And that was, who?

Could you say more about that?

What else comes to mind?

Smiling

Yes

What was that like?

Anything else?

What else happened?

Wow!

Interesting.

APPENDIX E
Counseling Referral List

Referral List for Persons Participating in the Study

The Family System and Alopecia Areata:

A Phenomenological Study of Family Members' Lived Experiences

Denton, Texas

Counseling and Family Therapy Clinic
Texas Woman's University
Human Development Building, Room 114
Denton, TX 76204
(940) 898-2600

AAMFT (Therapist Locator)

American Association for Marriage and Family Therapy
<http://www.aamft.org/therapistlocator/>

Appendix F
Initial Telephone Script

Telephone Script

For callers asking about possible participation in the study

“Hello.” [Caller identifies self]. “Yes, this is Barbara Buchanan. Thanks for calling about my study. The purpose of my research is to explore the experiences of persons diagnosed with alopecia areata. Not a lot is known about what it’s like to live in a family with someone who is dealing with this condition. I’m interested to learn more, so I’m conducting confidential interviews with the family members 18 and over who choose to volunteer to tell their stories.” [Pause for response.] “What questions do you have about my project?” [Answer any questions.] “The study is a part of the requirements for my PhD degree in Family Therapy at Texas Woman’s University.”

“May I schedule an interview with you?” [If the person lives at too far a distance for a face-to-face interview, ask] “Would you like to set up a telephone interview with me?”

[If NO] “Do you know someone else who’s a family member of a person diagnosed with alopecia areata who might be interested? If so, would you pass my contact info along to them? Thank you very much for calling me.”

[If YES face-to-face interview] “Do you want to suggest a quiet, private place we could meet or I can suggest some places.” [Arrange the face-to-face interview. Repeat the day/time/place to be certain it’s clear.] “Any other questions?” [Respond to any questions.] “Thank you very much and I’m looking forward to talking with you soon.”

[If YES, telephone interview] “So we can arrange the telephone interview, first I’ll either mail or email the Informed Consent for you to sign and return. What mailing address or email address would you like me to use? There is a potential risk of loss of confidentiality in all email, downloading, and internet transactions. [Take down the mailing address or email address.] Once I receive your signed consent form, you can call me again at this phone number at the time we have agreed to for the telephone interview.” [Restate the time.] “Any other questions? [Respond to any questions.] Thank you very much and I’m looking forward to talking with you soon.”

APPENDIX G

Sample Master List for Participant's Results

