Research Study of the Lived Experience of Alopecia Areata for Women During Early Adulthood

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Abstract

Objectives: Alopecia areata (AA) is an autoimmune condition that causes baldness in men and women; however, it may be especially distressing for women given social standards and expectations for beauty. This sporadic condition can present with various extents of hair loss that unexpectedly relapse or remit across time. The present phenomenological study aimed to describe the lived experiences of early adult women with AA who developed it in pre-adolescence or adolescence, to provide greater understanding of the experience of having AA over time. ***Method:*** The present study is guided by phenomenological methods, including interpretive phenomenological analysis. Following in-depth, semi-structured interviews with six female participants ages 27-36 with current, active AA, who developed their AA between ages 10-16, data were transcribed and analyzed at an individual and general (i.e., cross case) level for themes. ***Results:*** Responses to initial awareness of AA or increasing hair loss were not uniform, with participants' psychological experiences ranging from not being bothered to life-altering and devastating. Physical sensations and visual reminders of increased hair loss can pull participants out of their everyday experiences, with possible helplessness regarding inability to stop the loss. Losing hair was sometimes experienced as a deep emotional loss, and was sometimes so devastating that years felt "dark" or "lost." Participants encountered uncertainty regarding when their hair might fall out, as well as unpredictabilitywith others' reactions. Participants often experienced normality with friends and family, but occasional rejection and derision from others led to certain spaces or situations feeling unsafe for revealing AA. Participants often concealed their AA with various approaches, including wigs or hair pins, which might lead to self-consciousness about the AA or wig being discovered. At some point, these routines become "automatic." Disclosing about AA to others increased vulnerability and openness, which might have negative (e.g., fear of negative reactions) and positive (e.g., deeper relationships) implications. The threat of AA being incidentally discovered can be distressing even after decades of having AA, but for some, making an intentional choice to reveal AA (e.g., openly telling others, not wearing a wig) led to freedom and comfort with the tradeoff of possible increased attention through stares or questions. ***Discussion:*** AA impacts individuals' lives in a variety of ways, and the impact can differ across time, situations, and relationships. AA can produce a great deal of distress that persists after more than a decade of living with it. For others, AA is less distressing. Psychologists and other providers might best serve individuals with AA by better assessing their individual experiences of the condition. Future research might investigate the process of how some individuals with AA come to greater acceptance of or appreciation for their AA.

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Alopecia refers to baldness or the absence of hair on typically hair-bearing areas of the body, especially the scalp (Venes, 2013). Alopecia areata (AA) is a form of alopecia caused by autoimmune attack of the hair follicles. This most commonly results in discrete, circular patches of alopecia on the scalp or in the beard region (Gilhar, Etzioni, & Paus, 2012). These patches vary in size from small (the size of a dime) to extensive (only a small tuft of hair remains), and frequently are distributed randomly (Olsen, 2011). AA can progress to its most extensive forms, alopecia totalis (AT) or alopecia universalis (AU), involving total alopecia on the scalp or the scalp and body, respectively. AA represents one of the most prevalent autoimmune conditions in the United States, as roughly 2.1% of the population develops it in their lifetime (Mirzoyev, Schrum, Davis, & Torgerson, 2014).

This relatively common disease is important to psychologists, as research suggests AA causes serious distress (Hunt & McHale, 2005a; Welsh & Guy, 2009) and is associated with reduced health-related quality of life (Liu, King, & Craiglow, 2016; Rencz et al., 2016). Some authors argue the distress is severe enough to qualify as a depressive or anxiety disorder (e.g., Hunt and McHale, 2005b; Tucker, 2009) and recommend mental or behavioral health treatment (Gupta, Gupta, & Watteel, 1997). Yet, extant studies often yielded contradictory findings that are limited by serious methodological flaws (Bemmels, 2015). More importantly, those studies are predominantly quantitative and hypothesis-driven, and lack details necessary to fully characterize what individuals experience in relation to their AA. There is a gap between what is known empirically about AA and individuals' realities. Qualitative, phenomenological research is ideal for addressing such a gap, as it results in rich detail that captures the essence of experiences (Wertz, 2005). Thus, it would provide psychologists a better understanding of the experiences of individuals with AA, an important perspective given those individuals may present to counseling and psychotherapy with AA-related concerns.

Features of the disease's course itself are illuminating of the types of experiences a person with AA might encounter. Studies of the lived experiences of AA primarily focus on capturing the detailed ways people cope with these and other experiences. The onset of hair loss is usually sporadic and rapid, and the course of AA overtime is unpredictable (Gilhar et al., 2012). Unsurprisingly, research has found individuals with AA cope with both the initial onset as well as the ongoing unpredictability (Welsh & Guy, 2009). Medical treatments are an active and adaptive coping strategy (Rafique & Hunt, 2015). There is no cure for AA, and available treatments often require continued use over the long-term (Hordinsky & Donati, 2014). Individuals with AA often feel disheartened by the lack of a cure, and will try multiple treatments in attempts at regrowth (Hunt & McHale, 2005a). Using medical treatments is common, despite their being painful and often unsatisfactory (Welsh & Guy, 2009). Hair prostheses (i.e., wigs) and other methods of disguising AA are available, and are considered a practical coping strategy for AA (Rafique & Hunt, 2015; Wiggins, Moore-Millar, & Thompson, 2014).

Rafique and Hunt (2015), in their study of the lived experience of AA, proposed the coping strategies their adolescent participants used followed a “causal progression” from maladaptive to adaptive coping across four stages: loss, concerns, negative emotions/thoughts, and coping. In addition to the abovementioned active (medical) and practical (concealing) coping strategies, their participants used support seeking, religion, acceptance, humor, self-distraction, and blaming. The authors proposed the participants chose more adaptive strategies as they lived with AA over time. Their study focused closely on describing the personal, psychological experiences of adolescents, rather than social, medical, or other aspects.

Welsh and Guy (2009) also investigated coping and the lived experience of AA, directing their approach to how adults who have had AA over a long duration cope with their body image. Relating their findings to the construct of body image coping with its three components (i.e., avoidance, appearance fixing, and positive rational acceptance; Cash, Santos, & Williams, 2005), they asserted participants passed through the sequential stages of avoiding acknowledging the possibility of ongoing AA, concealing their AA with various strategies, and eventually coming to concealment or other strategies that provided a greater comfortability and a sense of control. Welsh and Guy described personal, psychological experiences, in addition to some of the ways AA can be experienced socially. For example, they noted concerns about AA being noticed by others, participants withdrawing socially, and seeking social support.

Other qualitative studies, with diverse methods, have incorporated greater awareness of the experiences of individuals with AA as they interact with their world. Hunt and McHale (2005a) proposed the results of their grounded-theory analysis, with personal, social, and medical categories of experiences, are all related through their relationship to the social psychological construct of identity. They based this assertion on theory that physical appearance is an aspect of identity (Carr, Harris, & James, 2000), thus the major change of hair loss would be inextricably linked to identity change. Hunt and McHale (2005a) argued the experiences described by their participants, especially problems managing personal (e.g., distress, coping) or social (e.g., work, relationships, social support) aspects of AA, were thus the downstream effects of an identity "damaged" by AA (p. 46).

Wiggins et al. (2014) used discursive analysis to exclusively study the social implications of wearing a wig for individuals with AA. Their study was inspired by Goffman's (1959, 1972) theory that individuals are obligated by a social contract to "present themselves as they are" and not "deceive" others, especially close friends or relatives (Wiggins et al., 2014, p. 156). Thus, wearing a wig presents a potential dilemma, as persons with AA would have to choose to whom they will disclose it. The authors argued their results showed participants interacted with strangers, acquaintances, and close others (friends, family) in different ways. They concluded, "the daily work put into concealing hair loss and managing the noticeability of wigs is itself a huge interactional and personal burden for individuals" (p. 164). Thus, the experience of AA goes beyond wearing and styling wigs, to interacting with others about their use of wigs and other methods of concealment.

While AA occurs with a similar frequency in both men and women (Mirzoyev et al., 2014), research suggests their experiences may differ in key areas. Understanding the experiences of AA for both men and women is likely important for psychologists. Current research suggests, however, experiences with AA may be especially impactful for women. For instance, Hunt and McHale (2005a) found women with AA reported perceiving themselves as having greater difficulties from alopecia than their male counterparts. Moreover the authors identified fewer instances of coping and acceptance in descriptions from female participants as compared to male participants. Gender differences have been seen in quantitative analyses as well. Matzer et al. (2011) found female participants rated themselves as having a greater amount of stress due to AA than male participants, and Cartwright, Endean, and Porter (2009) found significantly reduced quality of life for women as compared to men. Clearly, there appears to be a need to understand the experiences of women with AA.

The present study is a qualitative, phenomenological investigation of the lived experience of AA over time for women diagnosed with AA who are in the developmental stage of early adulthood (ages 25-40) and developed their AA during pre-adolescence or adolescence (See Appendix A for Rationale). The approach in the present study goes beyond previous phenomenological studies of AA that focused specifically on coping, to capture more broadly the personal experiences of AA, including the ways in which individuals experience AA in social interactions. The research design for the present study was guided by a constructivist-interpretivist paradigm, wherein the goal is understanding phenomena (reality) that are constructed in the individual’s mind (Ponterotto, 2005). Thus, in the present study, the aim was to understand how individuals mentally experience their AA – what do they think, feel, do, or sense regarding their AA when they are interacting with the world? Given the assumption that phenomena exist in the mind, phenomena are then both subjective and hidden (Van Manen, 2014). A deeply reflective approach involving contact between researcher and participant is therefore needed to bring understanding of the experience to the surface and into language. The study methods involved a modified version of Seidman's (2013) phenomenological interviewing series to capture experiences with AA from the context of life pre-AA, onset and diagnosis, additional experiences up to the present, and participants' perceived meaning. Research questions for the present study include: (1) What do early adult women with AA experience? and (2) How do they experience it?

Method

Research Design and Philosophical Assumptions

The present study uses phenomenological methodology, drawing from Van Manen's Interpretive Phenomenological Analysis (Van Manen, 1990, 2014) and Wertz's Phenomenological Psychological Method (Wertz, 2005, 2011), as guided by a constructivist-interpretivist research paradigm and relativist ontological foundational belief (Ponterotto, 2005; See Appendix B for definitions). Phenomenology is a qualitative research approach with the goal of understanding what it is like to live through a given phenomenon (Van Manen, 2014). The use of the words "to live through" is intentional; it is not merely to live with something. The goal of this methodological approach is thus to capture the fine details of example moments in which the participants experienced AA, and to linguistically articulate those moments in a way that evokes or stirs an emotional understanding in the reader (Van Manen, 2014).

Participants

The investigator used purposeful, criterion-based sampling to recruit six female participants with self-reported, dermatologist-diagnosed, active AA. Inclusion criteria were female gender, approximately 30 years of age, reporting initial hair loss occurring at adolescence or pre-adolescence, and residing in the United States.

After approval for the study was granted by the University of Minnesota Institutional Review Board, recruitment began in the spring and early summer of 2016 through local and national AA support groups (See Appendix B for details). A sample size of six was arbitrarily pre-determined and selected to capture in-depth descriptions while maintaining a manageable amount of data. The first six individuals who met criteria were invited to participate. Participants provided informed consent, and selected whether to complete the interview in-person at a site of their choosing (n = 1; only an option for local participants), over Facetime (n = 1), or over the phone (n = 4). Each participant received a $20.00 gift card after upon completion of the second interview as compensation for time and effort.

Data Collection

The interviews followed a semi-structured interview guide (See Appendix C) based on a modified version of Seidman’s (2012) phenomenological interviewing approach. During interviews, this investigator encouraged participants to describe concrete examples of events with alopecia areata accompanied by description of feelings, thoughts, and behaviors experienced around those events. Participants completed 1-2 individual interviews, with some participants covering content of two interviews in one session. The differing number of interviews came about from individual variation in how much participants had to say about their experiences with AA. Interviews covered participants' initial experiences with AA, their day-to-day experiences of AA at the present time, and their perceived meaning of their experiences. All interviews and follow-up contact were audio-recorded. Total time in interviews varied from 86-184 minutes (*Mdn* = 107.5).

Data Analysis

The analysis proceeded through several steps, as depicted in Figure 1. See Appendix B for additional details.

Bracketing and reflexivity. The investigator used reflexivity and bracketing approaches throughout data collection and analysis in attempts to limit the impact of her biases and assumptions. Bracketing involves personal reflection and reflective journaling about potential biases (also called the reduction or epoché by authors including Van Manen, 2014). This process included noting inclinations to focus on the validity of participants' experiences as opposed to the person's truly subjective experiences (Van Manen's experiential epoché – concreteness), to view narrative reflections through previous theories or research findings (Van Manen's hermeneutic epoché – openness), and to interpret findings from pre-understandings of personal experiences (e.g., from previously interacting with individuals with AA). Finally, Van Manen explains, the researcher must use a methodological epoché or approach, "a flexible rationality is required that is able to invent an approach for investigating a selected phenomenon in a scholarly, creative, and original manner" (p. 226-227). Thus, the present study utilized an analytic approach combining useful features of phenomenological methods described by Wertz (2005, 2012) and Van Manen (1990, 2014).

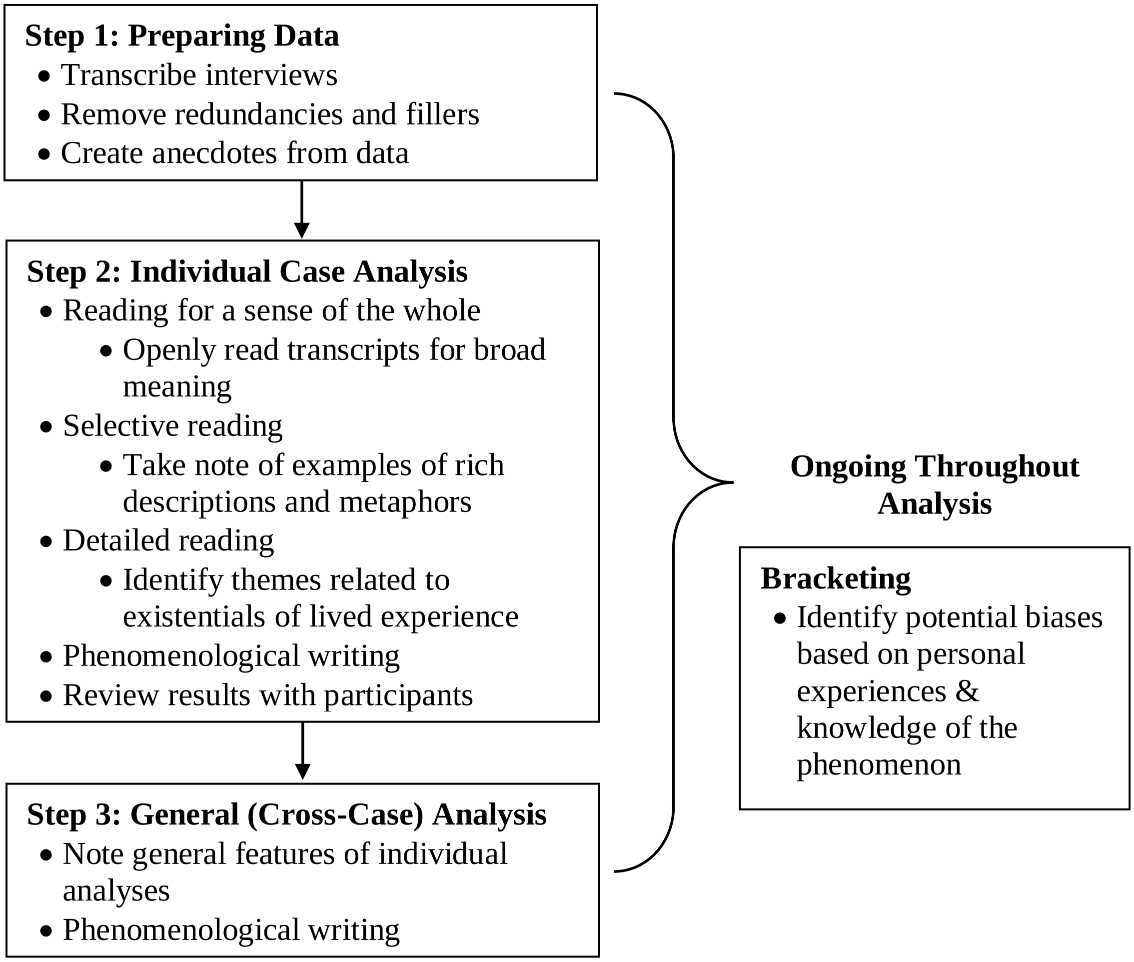

Figure 1. Procedures for data analysis in the present study.

Preparing the data. Data analysis began with the investigator transcribing data verbatim, and then transforming the data into anecdotes using Van Manen's (2014) approach. Anecdotes are not direct quotations; rather, they are participants' descriptions of their lived experiences edited (rewritten), as Van Manen (2016) suggests, "by deleting extraneous or redundant material and retaining theme-relevant material" (p. 254).

Individual analysis. The next phase of analysis was an in-depth, phenomenological case study of each participants' transformed anecdotal data. Using a hybrid of Van Manen (2014) and Wertz's (2011) approaches, the investigator used phenomenological writing to draft a detailed text composed of her reflections surrounding participants' anecdotes. In creating this draft, the investigator first re-read each participant's full set of anecdotes multiple times to: (1) understand the holistic essence of each participant's data; (2) selectively note potentially revealing statements about AA (e.g., rich or emotionally moving descriptions); and (3) identify potential themes relating to Van Manen's (2014) "existentials." Regarding the latter, the investigator noted what anecdotes revealed about how participants experienced AA in relation to others ("lived relation"), their body ("lived body,") – including how their body may be encumbered by AA, space ("lived space"), and time ("lived time;" pp. 305-306). Results of the individual-level analysis are presented in Appendix D.

After the individual analysis were completed, all participants were invited to participate in a participant feedback procedure. This procedure entailed sharing the complete individual results with each participant who responded (*n* = 5 of 6, response rate: 83.3%) over email, and a brief phone interview (*range*: 5-15 min.) in which participants were invited to share their reactions.

General analysis. In the final phase of the analysis, the investigator used phenomenological writing to analyze results of the individual-level analyses and the reflective journaling/bracketing. Themes were identified according to their being revelatory of participants' psychological experiences (e.g., thoughts, behaviors, emotions, physical sensations) or Van Manen’s existentials.

Investigator’s Perspectives

The investigator worked for five years as a research assistant to a dermatologist who specializes in diagnosing and treating AA. She also has training in counseling psychology, and experience with interviewing as well as with multiple psychological theories and interventions. She used knowledge and experiences in these realms during the aforementioned bracketing procedures.

Results

Participant Demographic Characteristics, AA Histories, and Feedback

Demographic characteristics of participants are presented in Table 1. Pseudonyms are used to protect their identities. Everyone self-identified as White/Caucasian or European ancestry, and had at least some college experience. All participants had unique alopecia areata histories, with variations in extent of AA across time. Every participant regularly used a wig at some point, and only one individual no longer ever uses a wig (pseudonym Halle). Only one participant is a parent (pseudonym Gabriella). Of the five participants who responded to the invitation to complete a feedback procedure, all noted the findings of the individual analysis were appropriately consistent with their descriptions from the interview(s).

Table 1.

Participants' Demographic Characteristics

Pseudonym	**Age**		**U.S. Geographic Area**		**Marital Status**	**Education**[a]
	At AA Onset	**Current**	**At AA Onset**	**Current**		
Bella	10	27	Midwest	Midwest	Single	Undergrad
Ashley	12	30	Midwest	West	Engaged	Some College
Rachel	13	29	Midwest	South	Engaged	Grad/Prof
Gabriella	14[b]	36	Midwest	Midwest	Married	Grad/Prof
Halle	15	29	West	South	Single	Grad/Prof
Sienna	15	31	South	South	Single	Grad/Prof

Note.
[a]Undergrad = completed an undergraduate degree. Grad/Prof = Completed graduate or professional degree. [b]Diagnosed at 7 years of age because of fingernail abnormalities characteristic of AA. Noticeable hair loss started at age 14.

Results of the General Analysis

Themes for the present analysis are illustrated in Figure 1 (with shortened titles) with arrows indicating the temporal relationships between themes/sub-themes in the left hand figure, and themes without a clearly temporal relationship on the right-hand side. Themes are described in further detail in the following text. In both the figure and the text, experiences are not mutually exclusive and may occur simultaneously or across themes. The primary form of presenting participant's descriptions of their lived experience throughout is with anecdotes, which are not direct quotations. Anecdotes are modified extracts from interview transcripts, presented below as block quotes surrounded by the researchers' reflections, questions, and interpretations.

List of themes and sub-themes:

1. Psychological responses to onset, awareness, and diagnosis.
2. Psychological responses to AA changes.
3. Managing AA

    1. Fatigue with AA management, limitations, and/or distress.
    2. Routines become "automatic."
4. Positive and negative social encounters.
    1. Family, friends, and activities: Finding normality.
    2. Rejection: "Rude" comments reduce the "comfort zone" for living with AA.
    3. Vulnerability of disclosure.
    4. Interactions with the AA community: Seeing new perspectives.
    5. Choosing to live with AA public.
5. "Lost" time and "dark" periods.
6. Uncertainty.
7. Changed realities/Pivotal moments.
8. Individual differences in emotional experiences over time.

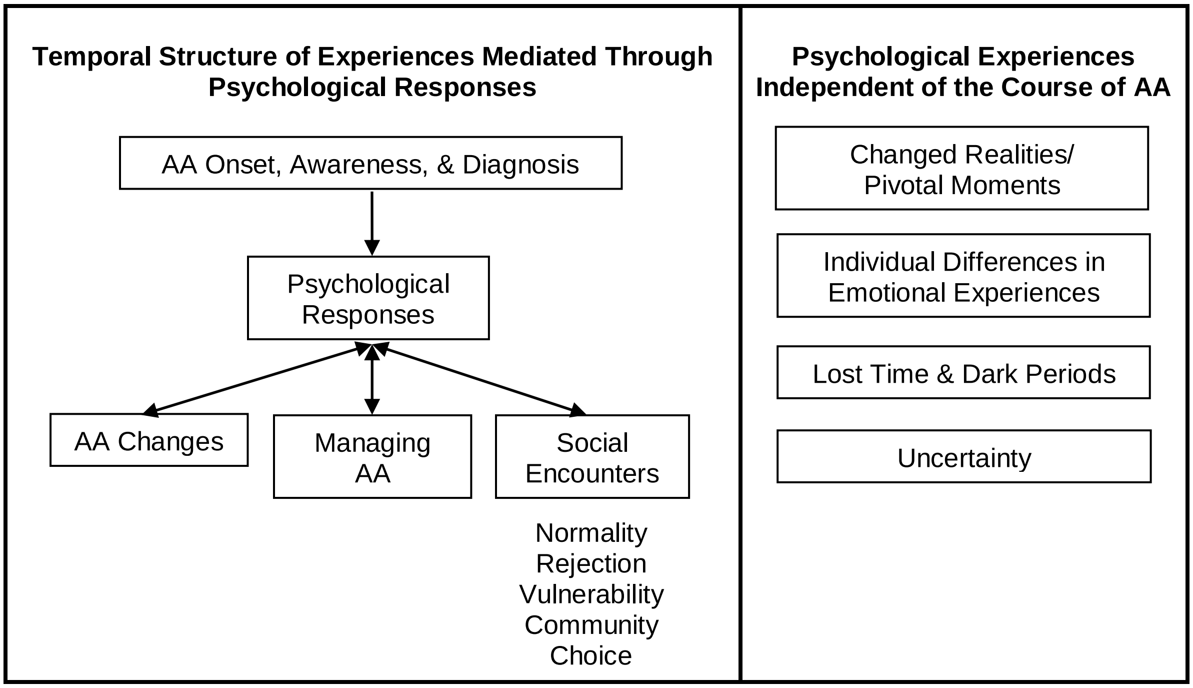

Figure 2. Relationships between themes and sub-themes describing the experience of having AA across time for women who developed AA in high school and are currently early adults. Themes are not mutually exclusive, and interact with one another across participants' experiences. The box on the left of the figure includes the temporal structure of themes and subthemes as mediated through psychological responses. The box on the right of the figure includes themes representing psychological experiences that occur independent of the temporal course of an individual's AA. Those themes are listed in alphabetical order to emphasize the lack of a temporal course of events.

Psychological responses to onset, awareness, and diagnosis. Participants' responses to the awareness of their AA followed a continuum from barely noticing to life-changing. On the less-impactful end of the continuum, one participant proposed the onset of her AA was a rather unremarkable experience.

> I just remember that it started as random thinning of my hair. I had a receding hairline. It didn't really bother me. I didn't think I was ugly or that I wasn't good enough. I was so active, I was so busy that it didn't really faze me. –Sienna, age 31, dx at 15

Another participant described not initially noticing her AA, because she had a generally low awareness of her appearance.

> I didn't even know it happened really. Being 10, you're not super aware of things. We were in the bathroom combing my hair. I remember looking in the mirror, and at that moment my mom saying something like, "Oh, your hair seems a lot thinner. Have you noticed?" And then me looking in the mirror and being like, "Oh, I didn't even notice." It hadn't really dawned on me. I was like "Oh, okay." Kind of just how kids react to stuff. I don't remember having any feelings about anything until I started seeing people. It didn't even register. I don't think I was really looking at myself. You look at yourself and you're like, "Oh, okay, that's me I'm in my clothes." It was one of those things I was completely oblivious to until somebody pointed it out to me, and then all the sudden it became a bigger deal. –Bella, age 27, dx at 10

While she previously viewed her appearance neutrally, it came to take on greater significance.

Gabriella had learned at seven years old what AA was, despite experiencing minimal hair loss at that time. Her first episode of noticeable hair loss came into awareness abruptly, and in an "instant" she knew what it was because of the experience in her youth. She rapidly passed through various reactions in the moment– questioning, uncertainty, denial, devastation, and searching for meaning.

> I think I was in the shower and realizing that my hair was coming out more than normal. With the idea that I already knew that it could happen – it was kind of an instant, "Yeah, I know that's what's happening." I know I sat there and cried in the shower. I didn't know how to react. I think there was this devastation that it was happening. But then at the same time my religious background kicked in and said, "You know what, I'm strong. God gave me this because I'm strong, so there's a reason I have it." Then, also, there was the thought that, "Okay, maybe it's not?" There is not much that I totally remember, other than what my first reaction was and crying, and thinking "Why me?" I know it was a long shower. You really don't want to remember those things. –Gabriella, age 36, dx age 7

Awareness of hair loss for some brought about concerns for health. When the AA began for Halle and Rachel, they wondered if it was a side effect of recent injuries and/or other maladies.

> My dad was driving me home from cheerleading practice. And I had a spot. I said to him, "I'm not going to be comfortable until I know what this is." I was distinctly aware that something was wrong. A year before that up until the alopecia, I had two or three head injuries while I was cheerleading. I was thinking to myself, "I won't be able to enjoy the holidays," "I won't be able to focus," and "I won't be able to move on." I felt uncomfortable not knowing what was going on because I was a fairly healthy person. But I was having trouble cheerleading; I was getting hurt a lot. I was getting nervous. There are always those horror stories in cheering. Like a girl was doing a tumbling pass and hit her head, and then never walked again. That was where my underlying subconscious fear was. –Halle, age 29, dx at 15

> About 2 weeks after the pool accident happened, as I was still recovering, I noticed little small patches, like quarter-sized patches of hair coming off my head. I had these small bald patches. It was sort of weird, and my mom and I didn't know what it was so we went to our doctor who said, "It looks like you have developed alopecia from this very traumatic pool accident." It was just concern about side effects from my accident. There was some concern if I was going to have sinus issues or if I had a broken sinus. –Rachel, age 29, dx at 13

Ashley experienced strong concerns about the potential implications for her health. The fears were serious; rather than thinking about her appearance, she thought of cancer.

> My family, we were on vacation, and I was in the bathroom. I was just running my hands through my hair and I felt the bald spot. It was something I had never felt before, so I started looking in the mirror. And it was on the back of my head, so it wasn't super easy for me to see. I sat there like, "What is this?" Trying to look in the mirror. For some reason in my teenage or pre-teenage mind, I thought I had cancer. Because the only things I knew that made women bald was [sic] cancer. I ran up to my mom and I'm like, "Something's wrong with me!" I sat down on the floor. My mom was on the couch and she took a comb and went through my hair. She found that spot, and it was about the size of a silver dollar. I was just hysterically crying because I thought I had cancer and I was dying. She called the doctor and they said, "You need to bring her in, we need to look at it." And my mom and I left vacation early to take me to the doctor. I was fearful because I thought that I had cancer. –Ashley, age 30, dx at 12

For one participant, clinic settings and the way providers interacted conveyed that something was seriously wrong. She was internally making sense of what she saw, which seemed ominous and threatening. She was no longer treated as a child.

> I remember it just being terrifying because I didn't feel like anything was wrong. So then all of the sudden we're seeing several doctors, and they all had funny last names and they were all really serious. They weren't child doctors who kind of play around with you and are really nice. And the specialist had like seven thousand other people in the room with her, because she's a teaching doctor, so I remember that being really intimidating. I only went to the doctor if either I was sick or if I had to have some sort of a check-up or shot. So, I think I start realizing that something is wrong with me; I wouldn't be at the doctor's if something wasn't wrong with me. And I think that's what's scary. I think then I started to worry like, "Okay, well what's wrong with me now? What do I have to do now? How is it going to affect me? Is this going to impact my ability to do the things I like?" –Bella, age 27, dx at age 10

Some participants insisted that in the moment they did not understand what was happening, did not grasp the implications of being diagnosed with AA, or were in denial that their disease would worsen. As an example, Ashley explained the interaction with her nurse practitioner:

> She came back with this book – she had it bookmarked – and she showed me a picture of a person with alopecia areata. She said, “It could be this." And right next to it was a picture of someone with alopecia totalis or universalis. I think I had this sense of, “It's not going to happen to me.” It never occurred to me that medicine couldn't fix something. It didn't strike me as maybe this could be something that they can't solve. I think I was primarily just thinking that medicine is going to solve the problem, because no one in my family had ever been *really* sick where medicine had not helped them get better. I believed some pill or treatment or cream would solve the problem. –Ashley, age 30, dx at age 12

Psychological responses to AA changes. Participants at some time experienced changes in their AA. They often noticed increased hair loss during familiar activities, such as showering, shaving, or changing hats. For some, visual reminders of hair loss were very distressing. One participant’s experience losing her hair for the second time in college elucidates how those visual cues might build like a crescendo as hair from various parts of the body sheds. The hair loss ends with devastation in the shower with “clumpfulls” of hair in her hands.

> I ended up losing all my hair. It was just really bizarre because it kind of went from my legs first, but like my left one then my right one, all the way up my body honestly and into my armpits, right side then left. My eyelashes, right side then left side. Then my eyebrows in the same way. And finally, like, 6 months later, it was holiday break for school, and the hair on my head that I had been holding on to started to go. When it got to the hair on my head it was in the shower, and I was pulling it out by the clumpfulls. It’s like, "Yeah, this is it." And then devastation, and "Why me?" Lots of crying. Definitely worried. And by the time I got back from winter break I had no hair on my entire body. I think I had a couple strands on my head, but that was it. –Gabriella, age 36, dx at 7, onset at 14

Sometimes participants would try to avoid the visual reminders because of how stressful it was to see them.

> Showering was really stressful for me during that time. I think I'd go a few days without showering, because the thought of going in the shower and

> washing my head, and having hair in my hands when I got out, or coming out and seeing hair on the bottom of the shower, I just was like, I can't deal with that. It's too much. Showering was a super stress-inducing activity. –Rachel, age 29, dx at 13

There might also be physical sensations that warn of or signify greater hair loss, including scalp tingling or feeling the hair run down the leg in the shower. One participant described a feeling helplessness, as her physical sensations would pull her out of everyday experiences.

> I could tell when my hair was going to fall out. It would tingle. There's kind of a burning sensation, like someone has your hair in a ponytail, and they're just like ripping it out of your head. And so that was stressful because I'd get these tingling sensations that were kind of painful, and I'd be like, "Oh my God, crap! I'm going to lose more hair!" I know what that means…I didn't have the ability to control it. I knew it was going to happen and I couldn't do anything about it. I could be doing whatever and not thinking about it, but my head hurt. And then I couldn't escape knowing that there's more to come. –Rachel, age 29, dx at 13

Losing hair felt like losing an important and beloved part of their body for some participants:

> My mom suggested that I shave my head because it was getting so bad, and I was losing so much. She started to shave my head, and I was just crying so much. She shaved my head to my scalp. It's a loss. I think I see it as losing a limb. My experience was that it was such a profound loss for me that it took me 10 years to find my new normal. –Ashley, age 30, dx at 12

> It was hard. I definitely felt like I was losing a piece of myself. That's how I describe it, or losing a really good friend. And I think as women we have these really close relationships with our hair, at least I think a lot of women do. I definitely did. I loved my hair until the very end, until I shaved it. And having to let go of that; I definitely went through different stages of grief. Really, I went through denial for a long time. I don't think I was ever really angry, but I felt a sense of loss as I was losing my hair. And shaving it all off felt like the final funeral for that piece of me. –Rachel, age 29, dx at 13

Yet increased loss and transitioning to wearing a wig are not always distressing. One participant likens getting a wig to purchasing an accessory, perhaps emphasizing the normality of the experience for her.

> I remember my junior year of college and the bald spots had gotten so bad that it was the whole crown of my head, all over, and behind my ears. It affected me to lose more hair, but I didn't feel crushed. It didn't really bother me. My mom suggested that I buy a wig. We got a wig that was similar to my hair. Being a girl, it was just like buying another accessory, like another pair of shoes. We went to the wig shop and I tried ones that I liked. I picked out a really nice wig. And that was when I started wearing the wigs and the scarves. –Sienna, age 31, dx at 15

Some participants experienced regrowth after an episode of AA. This produced a greater openness (e.g., to telling others) and sense of freedom. One participant's hair even took on a new value.

> I grew out my hair, and I grew it out and grew it out and grew it out until it was really, really long. So about three years later, I had it very long. I don't think I had ever had my hair that long before, but I was like, "I'm not cutting it ever again! It's too valuable!" I had it really long in all my senior class pictures, and once school started I went and got it cut short. And then I had fun for a number of years growing it out and cutting it, and having all these different styles and things like that until I was 21. –Gabriella, age 36, dx at 7, onset at 14

Whereas Gabriella's hair was once merely hair, losing and then re-growing it caused it to take on special significance.

Managing AA. Participants tried multiple medical treatments to manage their AA, attempting to stop their hair from falling out or trying to regrow it. They experienced discomfort with treatments – physically and/or socially.

> Having cortisone shots was the worst pain of my life. My gosh, that was horrible! I remember when they would do the shots on my forehead near my temple; that was the worst. I really had to be strong in the moment. I could feel the medicine go in my head, and it would burn. –Sienna, age 31,

> dx at 15
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> The Rogaine, I had to put on at night and then I couldn't wear anything over my head. I had to be totally bald for a couple hours so that it would dry. Otherwise you rub it all around your pillow, and then it will rub all over your face. You could start growing facial hair. At the time I had a wig, but if I went out in public I'd wear hats. I was bowling at the time because I'm a big bowler, and I was bowling with all the men and men's leagues. I can remember, I would have to go there without my hair on. I'm like, "Oh, man!" Because I have to go there and do this, or I can't bowl - which isn't an option for me. So I'd end up going in there without my wig. The word of what it is spread through there pretty fast. It's such a pain in the butt treatment. –Gabriella, age 36, dx at 7, onset at 14

Sometimes the strategies provided relief:

> And then the prednisone, all the stuff that they prescribed really helped because my hair started coming back. It came back rather quickly. So luckily in middle school I got a fresh start. I don't remember having any nervousness about it. I think by that point it was all back, for the most part, looking more normal. –Bella, age 27, dx at 10

Other times, treatments were less effective and caused negative side effects.

> The prednisone started to kick in, I was on like 60 mg a day for 6 months, and I think I gained about 60 lbs. over the course of the treatment period. I was tired. I was depressed from losing my hair anyways, and so that didn't help. I was too tired to move, I was sluggish, I was hungry all the time. And I was gaining weight from the prednisone alone, and then I was eating a lot of extra food. I'm losing my identity of what it is to be feminine and to be a woman from losing my hair, and now all of the sudden I'm turning into a balloon. My face was a moon-face and whatever feminine features I had at the time before I started prednisone were absolutely gone. Prednisone is probably worse than watching your hair fall out. But when you're losing your hair, you'll do anything to keep it. I think it's kind of a decision that's important because, what's worse? Losing your hair and you just lose your hair? Or losing your hair and you're fat? It's a double-edged sword. –Ashley, age 30, dx at 12

Participants had different feelings about and approaches to making treatment decisions, from clarity about not wanting treatments with adverse effects to greater difficulty choosing.

> For me, I wouldn't do any sort of treatment that would cause any reactions. I don't want something that's going to make me sick when I'm not sick just to get my hair back. It's not a big deal to me in that regard. I'd rather feel better. –Gabriella, age 36, dx at 7, onset at 14
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> I have taken 5 mg of prednisone every day for probably 2 or 3 years. My doctors are trying to get me to decrease that. Every year I go to get my eyes checked, and every year my doctor tells me my eyesight has gotten worse, when at my age it should have stabilized. It's getting worse because one of the side effects of prednisone is eyesight decreasing. For me, it's kind of like, well what do I want? To wear glasses or have hair? It's a tough one. I'm at this point, every year I go in to the eye doctor, every year I expect to see it has gotten worse, and every day I take the prednisone. It's a Sophie's choice. –Halle, age 29, dx at 15

AA takes on additional meaning knowing that some people, as in Halle's example, continue medical treatments despite risks to functioning. For Halle, both options have negative consequences, so the decision is not easy.

Participants might have, for a time, viewed their use of medical treatments as a sign they had not given up the fight. Stopping was then seen as resigning to a life with AA.

> Deciding to move on was hard because I think I felt in many ways like I was giving up. I had been fighting for so long. And I just thought: I could run marathons, why couldn't I fix my hair? I think there was definitely a mental adjustment that had to happen. The point when I started having really bad panic attacks was the point that I think did it for me. I could live forever like that, but it would be miserable. I have to find another solution, because this isn't working. I think I moved out of the denial phase, which I was in various states of. Maybe not denial, but just wanting to fight it. Having to give up the fight was really hard. –Rachel, age 29, dx at 13

Participants also employed strategies to cover the AA or otherwise keep it "secret." Often they felt self-consciousness associated with these strategies at some point. Sienna cited her only concern with her wig in college was that it looked natural; she merely wanted to maintain a "presentable" look.

> I felt self-conscious that other people knew I was wearing a wig. I wanted it to be so natural that people wouldn’t know. I would try and style the hair a certain way that it would look the most natural. As a woman, it’s an accessory to me. It’s not my hair. It’s just like when you wear anything with your outfit, or when you have your makeup on. If you put on fake eyelashes, I don’t want someone to know I’m wearing fake eyelashes. I take pride in getting dressed, and it’s a way to express myself creatively. I’m kind of a perfectionist, so I don’t like anything to be out of order. I just always wanted to be as presentable as possible. I want it to look natural. I don’t want to draw a lot of attention to myself. But just like any woman, I want to be beautiful. I want to look my best. But I don’t want to look like I’m trying so hard. –Sienna, age 31, dx at 15

Concealing the AA sometimes resolved self-consciousness and replaced it with security. When Gabriella lost her hair again in college, she found relief through getting a wig.

> I had this perception of what a college student should look like. I had been wearing hats. The first week back from break, I just sat in the back of the class. I wore a hat and kind of hid behind it. But I always liked to sit at the front of the class, and I wanted to be the person with this nice long hair. And after that first week back, I told my mom, "Let's go look at wigs. I think I'd feel more comfortable at school that way." Wearing a wig gave me back some of my confidence. I didn’t have to worry about what people are thinking. It was definitely a relief that no one would really know what's going on. I was just me. I didn't have to hide anything. It was my hair! It's not technically my hair, but it's hair! And it's mine! That was the relief with it, that I could be myself and have the confidence back. I could sit in the front of the classroom. –Gabriella, age 36, dx at 7, onset at 14

Some participants continued to experience ongoing insecurities about their wig being at the time of the interview, which would arise throughout the day for a variety of reasons. It might be environmental:

> There's all these sensory experiences; having the wind blow through your hair and being concerned about, “Is my wig going to fall off?” Having someone touch your hair. Like someone came up to me at work and grabbed my new wig and was like, "Oh it's so pretty." And I tried really hard not to flinch because I don't let people touch my head. –Ashley, age 30, dx at 12

> I don't necessarily think about alopecia every day, but there are days. Outside elements – I'm a huge hater of wind because my hair doesn't naturally flow like other people's. It doesn't look the same, I think it looks fake. So that's probably the only other time during the day that I think about it is when I'm with coworkers, and we're outside and the wind is blowing and I'm like, "Oh my gosh! Like what does my hair look like right now?" So that's kind of the only other time I think about it. It's just like hyperawareness. It's more of that anxious feeling. I'm like, "Oh, my gosh, like, are you looking at me?" Like, we're having a conversation, are you looking, like what's happening right now? It doesn't look right. So it's more of that. I can't think of a better word than just anxious. And it's like a judgment, are you looking at me and really listening to our conversation or are you looking at me and being judgmental and trying to figure out what's going on? –Bella, age 27, dx at 10

It might also be extra attention from others that draws the awareness to AA (e.g., compliments, glances), or concern the wig will be identified because it is dirty.

> Even when it's positive attention, when people are like, "Your hair always looks so good! I don't know how your hair always looks so great!" I always get uncomfortable. I just don't handle anything well having to do with the spotlight being on my hair. I think my heart races every time. But I also think I get a little tense. And I'm quick to change the subject. If somebody compliments my hair, I'm like, "Oh thanks." Then I move on quite quickly. I just don't want to dwell on it. I just don't want to sit there and make it seem awkward, like I'm hiding something either. I feel like I'm quick to jump to something else. –Bella, age 27, dx at 10
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> I think about alopecia if it's a day or two before I'm going to wash the wig and it's really dirty. Those are the days I tend to focus on it a little bit more in the morning, and I'm trying to make it look quote-unquote normal for what I think it should look like or feel like. I'm like, "I just need to get through today, and then I'm washing it and then I'll feel better about it." If it's getting kind of heavy, if it's not looking as fresh, I start to wonder if people are noticing and thinking about it as much as I am. It affects my whole day, I'm constantly going to the bathroom and checking it. –Bella, age 27, dx at 10

Participants also used strategies for concealing patchy AA (e.g., changing hairstyles, tinted dry shampoo), which for some was experienced with distress.

> The worse days were when I would get out of class and I would be kind of paranoid about one of my spots. Like, "Oh my gosh, I think one of my spots is showing. I think I felt a shift." Then I would run to the bathroom, and I would check in the mirror. I would re-adjust my bobby pins. I think those were the bad days; having a little bit of paranoia about “Are my spots showing? Is it really obvious?” I think those were the more stressful days. –Rachel, age 29, dx at 13
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> In high school especially, my anxiety – I can feel it. I became almost OCD about my hair, because I still had my own hair at that point but I was hiding stuff. So my mom wrote me a note to keep in my car that excused me for being late if I was having a bad hair day where I was obsessing over my hair or my hairstyle. That note is like a long running joke in my family because if I used it she would write me another one. I would keep it in my glove compartment and give it to whatever my first hour teacher was because it became a huge habit. I would curl my hair and I wouldn't like it, and I would have to re-straighten it. I would have to take a shower again. I'd have to re-do everything I had done in the morning, and then be late to school. –Bella, age 27, dx at 10
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> I had to learn how to change my hairstyle. And I do that to this day – changing my hairstyle based on my alopecia. I don’t know many people my age who are every month or two parting their hair on different sides. And I’m always making up some excuse or some reason. People, like some girl friends will say, "Oh, your hair is parted differently today. Why?" And I’ll be like, "I just want to try something different." That’s total bullshit, because I have lost so much hair on one side versus the other that I need to cover it up. So it’s hard. –Halle, age 29, dx at 15

In addition to physically concealing the AA, Halle made excuses as another strategy for keeping knowledge about her AA private.

Sometimes participants felt helpless about the limited options at their disposal for concealing AA, or the lack of guidance in the process. One participant felt lost in her first time shopping for a wig, and experienced negative consequences for not having better guidance.

> I remember frustration because a lot of wig places are geared towards wearing them for style, more so than disease. I ended up buying one from the second place we went. It was basically like: we went in there, I found

> one I liked, I tried it on, and I liked it and my mom liked it, and we went up to the cash register, payed for it, and left. Didn't know what to do with it, take care of it, what it was made of, nothing. I felt disappointed. Once I did find a good wig place, it was 6 months later and my other wig was destroyed because I didn't know how to take care of it. –Gabriella, age 36, dx at 7, onset at 14

When she eventually found a wig shop that took the time to educate her, she left feeling confident and well-informed.

> My stylist was my life savior. She's like, "I have time, come on back." And, so I went back and went through the whole thing. We went through everything. I knew when I walked out the door I looked like a million bucks, and I knew how to take care of what I got, too. It was a million-dollar experience. From there having that place and that outlet, I wore my wig every day, all day. –Gabriella, age 36, dx at 7, onset at 14

Rachel also found support and community as profoundly helpful when she started considering transitioning to wearing a wig.

> The support group online was how I figured out the different kinds of wigs, and the different kinds of hair you can get on wigs, and how much they cost. And that was how I gauged where to begin. It was a whole new world. I didn't know anything about wigs. Then I found what appeared to be the best of the best wigs, which are the wigs I have now. I contacted a woman who was the representative for my region. I contacted her and she drove up to my parent’s house, which was a solid 2 hours north from where she was. That was very kind of her. She also has alopecia, so that actually was really helpful. Now that I think about it, it's sort of amazing, she was the first person I had met in real life. It took me 8 years to meet someone like me. So I really trusted her, and she has never let me down. She's sort of been like my mentor. She's really well put-together, and she is beautiful and has great makeup and great hair. So it was like, "Oh, wow! Like she looks better than people who have real hair!" It felt encouraging. I felt encouraged and hopeful and less alone. And, I was just like, "Well, this person - they figured it out. I can figure it out!" And I have her to guide me, she didn't have anyone to guide her. It was really good. –Rachel, age 29, dx at 13

Seeing someone with AA who looked phenomenal provided Rachel with a new representation of who she could be (another example of an inspiring interaction with the

AA community, described later); wearing a wig and having AA did not mean she would have to give anything up.

When Gabriella's hair loss worsened in college, she also managed her AA in a unique way – educating others.

> I worked in the grocery store in the suburban town that I grew up. I would wear my wig during school and stuff like that, but on the weekends and when I was at work I would wear hats. I was playing softball with a news reporter with the local newspaper. I said, "Hey, will you do a story on me and my alopecia so that way when all these customers and coworkers come in they already know what's going on and they don't have to ask questions?" I did the story, and he did a nice job with it. It seemed to stop so many questions or weird looks. Everyone was just like, "Oh, she's in the paper. That's cool." I thought it was kind of exciting because I could really educate a lot of people all at once. Again, probably a little bit of relief that, "Okay, now all these people know, I don't have to hide it. And they know specifically what it is, they're not going to ask me if I have cancer or how I'm feeling." –Gabriella, age 36, dx at 7, onset at 14

Fatigue with AA management, limitations, and/or distress. Some participants were impacted in unexpected and perhaps dramatic ways by the strategies they used to cover their AA. For instance, with her patchy AA, Rachel felt "stressed" by her hair and the growing number of "restrictions."

> It got really stressful. It became more bad days than good days. I was really, really stressed out about my hair. It was so hard to wear it at all at that point because so much was lost. There was no way I ever could have gone swimming. I couldn't go out on a windy day. All these restrictions started coming into my life. I'm really active, and I never had that many restrictions on my life. So it felt really, really devastating, feeling like I had to live in this bubble where I couldn't be near water, near wind, or I couldn't get caught in the rain – otherwise my spots would all show.
> –Rachel, age 29, dx age 13

Some participants found the restrictions of wearing wigs stressful as well. For the year and a half that Halle wore a wig, she learned that wearing a wig means "everything that I loved to do was done."

> There is a multitude of things that you just don't even realize. Like when it's hot out, your head does not breathe and sweat like normal when you are wearing a wig. It's trapped in there. So you can't really do anything outside when it's really, really, really hot. Because then you are uncomfortable, and then you are sweating. Or you don't go swimming. And I'm from a place where we literally swim year-round. So you are not swimming, you are not running, you are not doing yoga. These wigs will come off. Everything that I loved to do was done. As I knew it, my life was over. –Halle, age 29, dx at 15

Some participants who limited their activities felt frustrated with the impact limitations had on others.

> I think I hold people back a little bit. Like my friend and I just went on vacation. I don't do snorkeling and that sort of thing, and her friends were like, "Oh, are you going to do this?" And she's like, "Well no, my friend's not a big fan of the ocean." It just *bums me out* that I hold her back from doing something. I'm like, "You can do it! I want you to do it!"–Bella, age 27, dx at 10

While important people can be supportive about limitations, they might also not automatically be aware of them.

> We went to like a great America Six Flags with my fiancé's sister. We haven't told her about the alopecia yet. I'm deathly afraid of roller coasters, so I wasn't going to get on them anyways. But I was like, "I can't get on some of these rides that even aren't roller coasters because the speed will take my hair off." And he was like, "Oh, I'm sorry, I didn't even think about that. It wasn't something that came to my mind." And that goes back to where people say, "If I had alopecia I would do this." I'm like, if you had alopecia you would have no idea what to do because there's constantly obstacles to how to keep yourself comfortable and how to keep other people comfortable. –Ashley, age 30, dx at 12

Medical treatments also potentially caused discomfort or limitations. For instance, when Sienna used a new treatment, her frustrations with the discomfort and tedium of treatments came to a head. After months and years of medical treatments, the time-consuming routine of this final treatment led her to say “enough is enough.”

> The doctor offered to treat me with a cream. I used it 6 days a week for 6 months or 10 months, and Wednesday was my only night off. So nearly every night I had to put cream on my head, and wrap my head with Saran Wrap. And my brother gave me the nickname “alien,” because I looked like an alien with my whole head wrapped with plastic wrap. Then I would go to sleep. I would be sweating like crazy, because I had the plastic on my head. I remember the feeling of removing that plastic wrap when I woke up. It had my sweat and the cream inside, and it was like the worst feeling. I would just go right in the shower and wash my head. It wasn’t a fun experience. The treatment wasn’t working. That’s when I just felt so sick of it. After that I just wasn’t motivated to try the next treatment. I decided that the most important part of this process and a real treatment for me is emotional. It has to be emotional because physically nothing is working. –Sienna, age 31, dx at 15

Some participants were just starting to reflect on whether they might want to change their approach and let the limitations of treatments or methods of concealment impact them to a lesser degree.

> You're either covering it up or you're on display, which is scary to me - I never liked being the center of attention. I don't like being on display. So walking around with a bald head or a scarf, that's not my comfort zone. But it's also not fun knowing I could be wearing a wig forever, and that's not totally myself either. I’m living in a weird in-between. Neither way for me is me. And that sucks. Knowing that that might be where I live forever is in the weird middle. I will never feel comfortable walking around with my head out. Even if I'm 80 years old, that will never be. And as cool as wigs can be, you still know that it's not yours. Like my nieces pull my hair, and I'm like, "Oh, I probably should react," but you don't feel anything. It's weird to not feel a sensation. So that's weird. So realizing that it's a thing is still hard. It's just a weird feeling. As much as you can embrace it, it's still never a comfortable feeling. Maybe I'll get there someday, but I just don't feel like that's me. That's just not who I see myself being is the person that, fully embracing, wears a scarf all the time. I just don't see myself fully embracing that, and being comfortable with it. –Bella, age 27, dx at 10

> I hope I can let it dictate less of my life. I don’t really perceive that happening, because of this constant fear. If I figure out that if I’m not stressed and I eat a gluten free diet, my alopecia is okay – why would I

> change that? Why would I bring on alopecia if I don't need to? That being said, I also want to live my life. It's very, very hard, but I try to be a little more open with people, which I'm not doing a terribly good job. When I meet people, I just know if they are going to be understanding or not. I think in the future maybe I'll give people a little bit more of a benefit that they will be understanding. I would hope they would be. –Halle, age 29, dx at 15

Bella mentally worked through her options, recognizing that where she is now is a liminal space in which none of her options really "feel like me." Similarly, although Halle felt tired of the ways her AA restricts her life, she expects herself to continue focusing her life on efforts to stop the AA from increasing and continuing to keep it private.

Routines become "automatic." Some participants talked about how their routines regarding AA have now become "normal" or "automatic." It is as if those participants have experienced their routines as a passed through experience – one in which they are rarely ever pulled out of their unconscious experience of the world.

> I guess for me everything is pretty automatic at this point. I just wake up. I don't really give too much thought to any of it. I'm able to just throw my wig on, brush it out a little bit, and out the door I go. Not much in the way of any of that. I don't really give any thought to any of it all day because I wear a wig, so no one knows. I just go along about my life. I honestly can say I don't really think of it at all. In the evenings, like after work and whatnot, usually I just want to pull my wig off. In a typical day I usually just keep it really close. I want to pull it off and if I do, I usually keep it really close in case the doorbell rings or I have to take the dog outside. Those sort of things. So I guess I think of it in that point usually mostly in the evenings, I think of the idea of having alopecia. But it's pretty automatic, I don't really dwell on it. And then I'm just relieved to take it off at night and set it on the wig stand for the morning. –Gabriella, age 36, dx at 7, onset at 14

> I don't really feel like it impacts my day-to-day life that much anymore. Putting on my wig is like putting on a pair of shoes or something. It's just very normal. I don't ever really think about it, other than like, "Oh, thank

> God I can come home and take my hair off." I would say it's not any more a part of my day than eating breakfast. I don't ever think about it. It's so strange. I just think I spent so many years fighting it, and now it's just part of who I am. It's not weird; I don't ever feel weird about it. –Rachel, age 29, dx age 13

Some participants have grown to appreciate aspects of their new beauty routines. Both Sienna and Rachel highlight how the objects they use to cover their AA are now special.

> A normal day for a woman living with alopecia for over 17 years now. I wake up, like anyone else, do the normal daily routine. I take a shower. I always wear a scarf daily. I love wearing scarves; it's so my thing. When I pick out my clothes, I always make sure that my scarf matches my dress, my shoes, and my jewelry. The scarf is just another accessory that I use, and it's a big deal for me. The way I wrap the scarf is different every day; sometimes I'll tie it on the right side, or in the back, or in the front of my head. Sometimes I'll put a headband on with the scarf. The scarf is just another way that I accessorize my outfit and make sure that I look nice. – Sienna, age 31, dx at 15
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> I wear fake eyelashes. I like to think of it as my trademark. You will never find me without my fake eyelashes. I put them on every day. I love them. I don't feel like myself without them now. I think even if all my eyelashes grew back I'd still wear them. –Rachel, age 29, dx age 13

Positive and negative social encounters. ***Family, friends, and activities: Finding normality.*** Close allies helped to maintain a sense of normality when confronting AA. Prior to the junior prom, a mom's nonchalant response signaled the normality of the experience.

> My mom was doing my hair, and she saw the bald spot. It was like an inch from my forehead. She just told me about it, and she said, "Oh, that's fine. We'll just fill it in with some dark brown eyeliner." For me it was like if someone broke their arm or they fell off their bike and got a scratch or a cut. It was just like, "Okay you got that." And you just keep moving forward. It was kind of like that for me. I wasn't like…"Oh my gosh! I'm so ugly. What am I going to do?" It wasn't like that. It was just like, "Okay. There's a spot. We're going to fix it right now by putting eyeliner

> on it.” And that’s what we did, and then I went on and had a great time at the junior prom. And it wasn’t a big deal. It didn’t really faze me. –Sienna, age 31, dx at 15

Other participants experienced minimal extra attention from friends and peers. Not being treated differently confirmed their continued normality despite AA.

> I think I was kind of lucky that I had a lot of chill-out friends, just because I was involved in music and band and what not. And no one really asked. I think they all kind of knew what was going on. We never talked about it. I just hung out like normal with my friends. I was very happy that no one ever really bothered me. Most of the time everyone pretty much left me alone. –Gabriella, age 36, dx at 7, onset at 14

> I told all my teammates about it so that they could help me braid my hair. We would always braid our hair in French braids before games. They were aware, I never hid it. I had a few trouble patches on the sides of my head and a little bit on the bottom of my head. I think it was just very matter of fact, like, "Hey, I'm losing these spots of hair on my head. Can you guys help me cover them?" I don't ever remember people being weirded-out by it. It was all very normal. I don't ever remember me feeling like I couldn't do things, or I couldn't tell people. –Rachel, age 29, dx at 13

Some participants appreciated, and even found solace in not being treated differently by family.

> Luckily I have a good family, and they've always kept me busy. That was my outlet to find somewhere, a safe place. I've always been super close to my family and they've never treated me any differently. It's just, that's kind of my, sanctuary-type thing. –Bella, age 27, dx at 10

Families did not always provide normality, however. One participant’s life at home changed to include limitations on what she could wear and where she could go.

> I had lost so much of my hair that my mom was making me walk around the house with a bandana. My mom wouldn't let me go in the kitchen because my hair was everywhere. Everyone would be in the kitchen… [where] there was a tile floor and then a divide. So my mom was like, "You need to stay on the outside of the tile divide." I had to sit in the living room while my entire family would be in the kitchen. It was almost a symbolic divide where you can't cross the tile. I just walked around with

> this bandana on my head, and just my hair continued to fall out in profuse amounts. –Ashley, age 30, dx at 12

Rejection: "Rude" comments reduce the "comfort zone" for living with AA.

Some participants encountered comments, mocking, or other unkind acts. One participant responded more with shock than hurt. For other participants, the hurt was very painful. Regardless, they learned certain spaces were not safe to reveal AA because of potential for insults.

> We were on the bus once and the kids that went to his [my boyfriend's] school, they broke CD-ROMs and were throwing them at me. And they were cursing at me and telling me, "What the F is wrong with you? You look like an alien. You're disgusting." And they were saying very hurtful, cruel things. It was very shocking to see someone behave like that, especially because I wasn't trying to do anything mean to them. They were just mocking me for something that I didn't choose; I didn't choose to have alopecia. I felt bad for them, and thought like, "They must be hurting in their life somehow that they could feel that it's okay to bring someone else down." I felt bad for them. My boyfriend and I decided that we were going to drive together to school and not take the bus anymore. –Sienna, age 31, dx at 15

> I had a spot on the crown of my head. A girl who I went to high school with asked my best friend if I was anorexic because she noticed my bald spot. That was obviously really, really hard. I was offended. For her to say something like that was obviously rude. I was upset that she had noticed. I was so upset because I thought I had been doing a good job covering it up. My fear was, "If she noticed, who else is noticing?" I think that was probably one of my first times of being like, "I need to do everything I can to cover this up. I need to be more diligent just about really checking everything." –Halle, age 29, dx at 15

Participants even carefully constrained behaviors to the "comfort zone," as certain ways of interacting, elements, or activities threatened to bring attention to the AA.

> I was just uncomfortable. I felt like I was behind and not totally in the group because I was too nervous to go outside of whatever comfort zone I had kind of created for myself. It made me more introverted, and I'm not an introverted person – I'm very extroverted. But when it came to when I

> have flare-ups, I just wouldn't want to do a whole lot. I found myself turning down activities because I didn't want to be put in an awkward situation where I was going to feel really uncomfortable. I feel like it stopped me from doing things with friends just because I didn't want to be put in a weird position. If it rained it made me nervous because my hair was so thin. It takes out pool parties, too. –Bella, age 27, dx at 10

Vulnerability of disclosure. Over time participants started disclosing their AA in various relationships. Disclosure opened them up or made them feel vulnerable. For some, disclosing evoked great apprehension or distress. Bella and Halle explained the context of their hesitation to disclose.

> You start experiencing people talking about you behind your back, and people asking a lot of questions. That's what I always equate having to tell somebody to. I always think they're going to react in a stuck up way. Kind of like, “What's wrong with you?" Because that's how I first was exposed to people knowing, or people asking, or people asking in an almost accusatory, judgmental way. –Bella, age 27, dx at 10

> I think it’s just really opening myself up. I think it’s kind of the fear of rejection. It’s an interesting way of looking at rejection, wondering if, “What if I do tell this to someone and they say, ‘Well now you're ugly’.” It has never happened, but I can’t imagine it won’t ever happen. I can’t imagine how someone wouldn’t be grossed out by it. Because you only see bald people with cancer. And people think those people are dying. So how do you know? I don't. –Halle, age 29, dx at 15

Despite experiences contrary to feared expectations, some participants still felt hesitant about sharing AA with people in their lives.

> My biggest thing is I always associate it with being a negative experience, but everybody I've told, it's made our friendships stronger and people understand me a little bit better once they know. But I think it was ingrained in me so young to associate it as negative. I do refer to it as posttraumatic stress because that's all I think of. “While I'm telling you, I keep expecting you to look horrified and be disgusted that this is a thing and I have it.” I tell everybody I'm an open book, but that's like the one chapter that’s on lock-down, and you have to be super special to get that. –Bella, age 27, dx at 10

Halle provides an example of how disclosing can be extremely uncomfortable, when during high school she encountered a situation in which she felt she had no choice but to explain why her hair looked different.

> I had lost the hair at the nape of my neck, and my coach for a competition had asked that our hair be worn really, really, really high in ponytails. And I remember just feeling so uncomfortable. I remember telling my coach or our team mom that I could only put my hair up to a certain height, and it was going to look different than everyone else's. There for a while in high school, I could count on one hand the people who knew I had alopecia. I kept it so close. I didn't want to tell anyone – I don't know if that's a defense mechanism. So the idea that I had to tell them, I felt like I was…practically, to be melodramatic…practically being held hostage by this. But I had to tell them, it was either look different and get scolded for not doing my hair correctly, or just tell them. –Halle, age 29, dx at 15

Romantic relationships presented a special situation vis a vis disclosure. Some participants found acceptance in this realm.

> I had boyfriends. I had good relationships with them. That was always fine. I do remember always telling each of them. They always reacted fine. It was never really an issue. –Halle, age 29, dx at 15
>
> I met my husband through mutual friends. They had known about the condition and were able to tell him before we even dated. So, I think it was pretty funny when I met my husband. We had gone out on our first date, and I kind of wanted to be open about it just to let him know right away, just because I'd rather tell people right away, especially people I really want to have a deep relationship with. I didn't know that he knew. He was like, "Yeah, I knew that. No big deal." I was like, "Oh. Okay. That works for me." –Gabriella, age 36, dx at 7, onset at 14

AA was attractive to potential partners for one participant, given it provided an opportunity to showcase confidence.

> Usually when I first meet someone I tell them. I remember meeting one boyfriend at a coffee shop. He was sitting at a table, and I sat at the table where he was sitting. We just started talking. I had a scarf on at that point. I'm just so moved when I meet someone. I'm really honest. Something in me just wants to tell people. I remember telling him about alopecia, and I

> actually pulled off the scarf and showed him the alopecia. He later told me that he was shocked that I was so comfortable to tell him. And he thought to himself like, "Wow. Maybe she thinks I wouldn't be attracted or that she is pushing me away, but I am actually attracted because she is so honest and so comfortable." –Sienna, age 31, dx at 15

Alternatively, some participants experienced negative reactions when disclosing AA in romantic relationships.

> The guy I dated before my fiancé, I had dated him for 3 months or so. I was at his house and I had told him about, "Hey, there's something I haven't told you about myself. I have this condition, I've had it for a long time." At first he was like, "You're beautiful the way you are." Later that week, he came over and had a bag of my things, and he was like, "I just don't know where this is going. You're a really nice girl, but I just don't see this working long-term." I was like, "I would rather you just tell me to my face. I know the reason you're breaking up with me and I want you to say it." Then he got really quiet and he said, "I thought about what you told me, and I'm just not okay with that. That's not feminine, and that's just inadequate," basically is what he said. I was really hurt, but I held back my tears…I didn't want him to see me cry because I didn't want him to know that that was my biggest insecurity. So I tried to hold my head up high, and the second I shut the door I burst into tears. That really destroyed my confidence because that was my worst nightmare coming true. And, I had never had that experience with other people to that degree, where I had been in a relationship with someone to that extent, and they were just like, "You're not enough for me because of this." It was really, a really painful, painful experience. –Ashley, age 30, dx at 12

Some participants found intimacy with romantic partners difficult, as being comfortable disclosing is a challenge. For Bella, her one exception to the discomfort was her ex-boyfriend from her "lost year" (described later). Still, she questions the source of her feelings for him.

> That's my biggest frustration with this, because I want to find the right person for the right reason. I don't want to settle, so that's where my struggle is with my ex-boyfriend. I don't want to make a decision on my future just because I'm comfortable with him because he knows about my alopecia. There is a lot of love there, but is there something more out there and I just don't want to figure it out? What's hard is getting out of that

> comfort zone because this whole disease makes me uncomfortable. So that's what's hard is being comfortable being uncomfortable, if that makes sense. Because I feel like I've put myself in a lot of uncomfortable situations and with relationships and guys, that's one thing that I am not comfortable being uncomfortable with. –Bella, age 27, dx at 10

Bella recognized that she may need to tolerate greater discomfort or ambiguity regarding romantic relationships, but still finds it difficult.

Ashley experienced adversity at work during college due to non-verbal disclosure of her AA (i.e., not wearing a wig or bandana). These experiences taught her to wear a wig at work, and she continues to do so to this day.

> In college I was working at a spa of a resort. I was wearing my wig to begin with, but as the summer went on it got warmer. I would get warm, and I'd be wearing this wig. So I stopped wearing the wig and I started wearing a turban. I followed the dress code, I came to work on time, and she [my employer] would say "Oh, why aren't you wearing your wig?" And I was like, "It's too hot. It's 100 degrees outside, I'm doing hot stone massages all day. I'm hot." And she kept trying to bring it up. One day she said, "You need to wear your wig when you work here. I hired you to be in the massage service." And I said, "I'm still doing my job, I'm just not wearing a wig." She said, "People are uncomfortable with you because they think you have cancer and you're massaging them and they feel bad." I eventually went to an attorney to see is this legal. No, it's a form of discrimination. There have definitely been instances *where people don't want me to be myself* because they were afraid that it would affect their business or they were uncomfortable, whatever the motivation was behind it. I'm not entirely sure. But, it happened to me enough times where I know from personal experience that I'm better off wearing a wig in a professional setting. –Ashley, age 30, dx at 12

Interactions with the AA community. Coming into contact with others who have AA in some way had special significance for some participants. As Rachel described, she had felt lost and alone with AA for years before finding support groups online:

> I think for all through high school and most of college, there wasn't a sense that other people had this. So I was thinking that I was alone, and that no one else had this. Thinking I was the only person in the world who

> had alopecia was really hard. There must have been alopecia support groups or some sort of resources. And I never knew about them. I definitely felt alone. And then I discovered online support groups, and that was really helpful. It must have been 2007, I had already had alopecia for like 5 or 6 years at that point. And basically, had thought the entire time I was this really strange case, like they had never seen anyone else with it. It was kind of before the age of the internet, so I had never done any research. It was just sort of this bubble that I was living in by myself. I think that once I found the support groups, Alopecia World was really helpful for me when I first discovered it. To be like, "Oh, there are people way worse off than I am." Or, to see how people are dealing with it. And I was like, "Oh wow, there's people all over the world that have this." I just found those really helpful. Just knowing that I wasn't the only person, I think that in itself was just really helpful. –Rachel, age 29, dx at 13

Participants' thoughts about considering different approaches to managing their AA or their inspiration for how they choose to respond to it might have been inspired by interactions with others. Some were inspired by the appearance of a confident and beautiful woman with AA.

> When I was it Italy I went to the grocery store right near my apartment in Rome. One of the cashiers, she was a probably a 50-year old Italian woman. She was very beautiful and confident. I don't know if she had alopecia, but she definitely had some type of hair loss. She literally had like 20 strands of hair, and wore them up in a scrunchie. She was so confident. It made me feel happy to see her in public like that, like it didn't even faze her. That always sticks in my mind that I saw that woman.
> –Sienna, age 31, dx at 15

Others found new perspectives through conversations, especially in the settings of support groups and foundation meetings. For instance, Halle was introduced to the idea of living life openly with AA when she saw others doing so at a NAAF conference.

> The type of people I met at the conference – they didn't care if they were bald or wearing a wig. They wanted to go and do everything. And me with a full head of hair I was still, I was the most self-conscious one. –Halle, age 29, dx at 15

While not revealing her physical appearance with AA, Halle opened herself up to potentially share her AA identity to acquaintances.

> Something that has changed. Since the conference, I want to be more involved with NAAF. Even going around on the day at the conference where we go up to the hill. We were doing legislative work, lobbying work, essentially. I have a lot of friends who work on the hill, so I was nervous they were going to see me. See me in this shirt and see me with people, and be confused. But I was kind of like, if I see them and I tell them, then that's their problem if they react negatively. So I don't know what I hope for the future. I hope that I can be a little bit less strict with myself. But I don't know. I guess we'll see. –Halle, age 29, dx at 15

Choosing to live with AA public. Some participants began to occupy certain spaces with AA exposed. This might be an occasional setting, and is experienced in different ways depending on the intentions and reactions of those witnessing the AA. Often the attention is experienced as curiosity.

> When I go for a run – I run a lot – I wear my baseball cap out. One time when I was running I had a little kid look at me, and then look at her mom, and go, "Mommy, what is it?" And I was like, "Uh, I can't even be mad." Like it's a little kid and they're confused. Because I'm obviously a girl, but I don't have any hair. And I wasn't offended or anything. – Rachel, age 29, dx age 13

Because Sienna chooses to wear a scarf daily, instead of a wig, she too has experienced inquisitiveness and attention on a regular basis. She is consistently reminded of her AA whenever she leaves the office at work because of the attention she gets from strangers.

> Throughout the day, like when I get coffee or have lunch, I'll find people looking in my direction. They might stare or whisper. I'll just smile at them, wave, and say "Hello." Maybe they will look away quickly once they see that I'm looking. Some people will think that I have cancer, and will come up to me and say, "Oh, how is your treatment going?" I tell them that I have alopecia and I use that as an opportunity to educate them about it, if they don't know what it is. It doesn't hurt my feelings, but it does get annoying when people will constantly stare or whisper. –Sienna, age 31, dx at 15

Sometimes participants found the attention came from a place of malice.

> One time I was by myself at the beach, and I didn’t have a scarf or anything on my head. There was a bridal party, and they were taking pictures on the beach. A couple groomsmen were looking my way. They were shouting and they were saying, "Oh, my gosh." They were cursing and saying nasty things about me and, "What the F is wrong with her? Do you see that over there? You should get that thing in the picture." And the thing he was referring to was me. I thought it was just very rude, disappointing, and frustrating. Here is an adult man who is trying to bully me. It was very sad in the moment. I just ignored them…I figured this wasn’t someone that was trying to learn about what was happening with me, or this is not someone that’s concerned with another human being. They are concerned with trying to be a comedian, and trying to impress others by bringing another person down. I figured it wasn’t even appropriate for me to say anything because it wouldn’t have made much of a difference. If that’s the mindset that they have, which is very evil, then I wasn’t even going to waste my words on them. –Sienna, age 31, dx at 15

Sienna was labelled by the strangers as a “thing” for being in public baldheaded. She experienced their rejection but did not internalize the rejection herself.

Some participants have experimented with not wearing a wig in a specific setting, and at the time of the interview were considering a transitioning to using this approach more broadly.

> Once I started wearing the wig, I probably hid under it a lot. I wore it all the time up until last summer, and that's when we started going camping and I wouldn't wear it on the weekends. So, a couple of my friends up there [at the campsite] know and have asked, and we've talked about it, but other than that no one else really asks. I'm guessing word kind of spread. I guess it was just pretty easy because it was a new thing for us. I was able to just kind of make the conscious effort. I don't really want to wear my wig when I'm up there. It's uncomfortable, and it's hot and I'm outside a lot. And, it's annoying. So, I just went there without it. And if people asked, I just told them. It felt good to be accepted for who I am and not have to worry about what anyone thought. I think it was a new opportunity for me to not have to wear a wig. It was all new people to me. It wasn't anyone existing that I had to reveal this years old secret that I had, or anything like that. It was just, this is just who I am, and this is what it is,

> and that's it. I didn't shock anyone. –Gabriella, age 36, dx at 7, onset at 14

Gabriella seems to find it easier to be open with her AA from the start, than to reveal to people that she had kept her AA hidden. She had difficulty finding the words to describe why she now prefers to go without the wig, but perhaps there is a greater authenticity to who she is.

> I'd have to say I do feel different when I don't have my wig on versus when I do. In everyday life where everyone knows everything about it, I feel so much more comfortable and so much more *me*. I can't even explain why I feel that way. I can't even say the feelings that come with it or anything like that. I just feel more comfortable with it off. After not wearing it on the weekends, I don't want to wear it all the time. But I don't know how to approach it now. I'm not just going to show up without my wig on to work. So I feel like I have to tell them. But how do you bring it up in everyday conversation? –Gabriella, age 36, dx at 7, onset at 14

Gabriella seems comfortable with other people knowing about her AA at this point. She has learned from experience that once people know they do not really care, and it does not change their perceptions of her or the way she is treated. For her the biggest issue and the reason she keeps it hidden in any situation is that she suspects the moment of revelation will be uncomfortable, particularly if she has already kept it hidden from someone when they first met.

As Sienna started covering or revealing her AA differently in accordance with her preferences, she experienced the world differently depending on how she presented herself. She calls this her “three-person life.”

> I have felt like this for many, many years. I feel like I’m living a triple life. I actually did a PowerPoint presentation about this. It’s just this crazy, three-person life that I have to live for my whole life. I’m getting positive attention when I’m all dressed-up with a wig on. I’m getting curious, negative attention when I don’t have anything on my head. And then with the scarf it’s like in-between; I get positive and negative. –Sienna, age 31,

> dx at 15

In Sienna’s description of these three presentations, nothing within her shifted. The three selves came about through the different ways people reacted to her different appearances. She alternatively experienced rejection, curiosity, or interest.

One participant, Rachel, also talked about how she now sometimes makes her AA public through talking about it.

> The only time I ever think about it is, like today for example, I wore one of my shorter wigs. And I had a co-worker be like, "Oh, hey you got a new haircut! I like it." Most of the time, I'll just be like, "Oh, it's a wig, it's not my hair." And they'll be like, "Oh." And then I'm like, "Oh yeah, I have alopecia." And then I'll tell them the story. People are always really interested to hear about it, and I think because I treat it now so nonchalantly that other people feel really comfortable; like no one ever is weirded-out by it. Everyone is like, "Oh yeah, okay." Or I'll make jokes. Like if I have a stressful day, I'll be like, "God, I just feel like pulling out all of my hair, if I had any left." People think that's funny. –Rachel, age 29, dx age 13

Interacting with coworkers about AA has gone well, which she attributes to her attitude.

Uncertainty. Certain aspects of living with AA were experienced with uncertainty, including uncertainty about whether treatments will work or how others will react to disclosure. While hair regrowth was appreciated, a difficult aspect of AA is that hair can sporadically fall out again at any time. One participant noted in her interview that uncertainty about losing her hair again has been a constant presence in her life.

> I don’t know why my hair grew back. I really don’t. There was an inkling, there was like an ounce of me accepting the wig that I had. If I had to wear it for the rest of my life, maybe I could. And then my hair started growing back. So that’s why now, every day since, if I notice a new patch or I notice my hair is going to fall out, it’s terrifying. So I think the overall day-to-day thought and feeling about alopecia is constant fear of just not knowing. Could today be the day when I lose all my hair again and have to wear a wig? I don't know, I really don't know. And it's a constant fear. It's

> a constant, constant struggle. The fear of the big unknown has become a very conscious stream of thought with alopecia. There is a constant fear of more hair loss because you don't know what is going to happen. And I don't know if fear is the best word to be using, but that's really the only word I can think of. I'm not a drug addict. I don't have family members who are drug addicts. But I do kind of wonder sometimes if there is any comparison to the way that someone who is a drug addict is always thinking about when they are going to get their next fix. I'm *always* thinking about it. It's never not on my mind. It's like I'm sitting there having a conversation with a colleague of mine, and then I play with a few strands of hair and one of them comes out. I'm right back to the alopecia. I'm *disconnected* from that conversation, talking about whatever. And I'm now thinking about the alopecia and getting worried about it. –Halle, age 29, dx at 15

The threat of more hair loss, no regrowth, and having to wear a wig has been "constant" for Halle. Each new patch of hair loss potentially confirmed her fear becoming true. The fear of more hair loss pulled Halle out of the world, out of time, out of social interaction. Everything has become mediated through her AA.

While doing whatever she can to minimize the threat of further hair loss (e.g., medical treatments, diet and lifestyle changes), Halle simultaneously made plans for a potential future in which her hair loss increases.

> In years past I have not been the friend I have wanted to be because of my alopecia. I've missed birthday parties, and pool parties, and just outings in general because of my alopecia. Even when I was living at home while I was wearing a wig - my best friend wanted to go to dinner for her birthday with her parents and 3 or 4 of her other friends. And I said, "No" because I couldn't face them all. That's the worst. It just makes me so upset. It's a minor miracle that my friends have not totally disowned me. For a year I was just not a friend to them – at least a year. Now I'm trying to make up for that time, which is hard to do when I live across the country. My same friend, she is turning 30 in a few months and I'm making it a point to fly across the country for two days. I'm not missing this. Because I don't know if next year when her birthday rolls around, if I'm going to be wearing a wig or not. I don't know that. So I need to really take the time now. –Halle, age 29, dx at 15

She recalled feeling unable to face important people before, and implied that she expects she might feel that way again.

Lost time and dark periods. For some participants, extensive and rapid changes in hair loss resulted in entire spans of time they described as “lost” or “dark.” For instance, Halle stated she felt like she lost her early 20’s when she was confronted by increasing hair loss.

> I lost all my hair in grad school. I didn’t have any. And I ended up wearing a wig for a year and a half. It was hard emotionally. Everything was very hard. I didn’t want to socialize. To this day, I feel like I lost my early 20’s. I was inside reading. I moved home and lived with my parents for the summer. I didn’t stay and get an internship like my classmates. It was very, very hard. I think I was just in a constant state of sadness. I was like a hermit. I didn’t want to go out. I didn’t want to socialize. I had a very, very, very severe social anxiety. I was always assuming people were talking about me or looking at my hair. I wasn’t ever around other people besides my parents and my two younger sisters, and even then I didn’t take my wig off around them. So that was very hard. Like in the morning, you want to just go downstairs and grab a cup of water before you start your day. Normally someone would just walk downstairs, not even batting an eye. I would put on my wig, and then walk downstairs. I was trapped. I was absolutely trapped in this situation. And it was very difficult. I didn’t know when it was going to end. I didn’t know if I would ever get better medically. I didn’t even know if I would get better emotionally. I was wondering, “Am I going to live with my parents for the rest of my life?” I didn’t know. I didn’t know what was going to happen. It was very hard.
> –Halle, age 29, dx at 15

She repeated, “I didn’t know,” emphasizing the uncertainty and powerlessness she experienced. She withdrew deeply. Her world shrank as she found fewer and fewer spaces comfortable, eventually only feeling comfortable without her wig when no one – not even family – was around. In retrospect, she viewed her time with the wig as time she was not living; it was time lost.

After high school, Bella experienced a dramatic change in her AA that resulted in a major emotional change as well. She explained this is both her “lost” and her “dark” year.

> College was a big deal. My dark year was in college where everything kind of went downhill. It was such a weird road, because it kind of went super-fast. The hair loss and just the time in general; I call it my lost year. We didn't know what to do. I didn't want to do anything, and I just wanted to hide as much as possible because it just seemed easier. And that's just not like me. I'm very outgoing and I want to be doing stuff. I just felt a completely different person. It was definitely the closest thing to depression that I've ever experienced, because I thought everything was just too much work. Too much work and that life just might be easier if I didn't have to do any of it. I definitely felt sadness, and loneliness, and just kind of broken. I didn't feel remotely like myself. There were times I put on a happy face, but for the most part I felt outside of my body. Everything that I was doing felt like it was just not me. I think I could have been fine just sitting in my apartment probably all day everyday just kind of shutting out the entire world. All I wanted to do was complain and talk about how terrible life was. This was basically my worst nightmare. –Bella, age 27, dx at 10

Having not faced hair loss of this degree since her youth, Bella felt out of her depth. Time seemed sped up, as she grappled with what to do. She came out of this period after finding a wig that allowed her to feel comfortable.

While not explicitly describing a sense of time being lost or dark, one participant attempted to erase the period in which her hair loss was increasing. She symbolically did this with photographs.

> When my hair was falling out and it got so bad - you know how you can have a fringe, like bangs - I had a little piece right here on my forehead and it was completely bald all the way around it. So it was like this little island. I have one photo of it, but I was into scrapbooking in high school, and all of my photos of me going bald, I cut around the hairline and cut all the balding out of it. I covered it with stickers or something. I just didn't want to remember that time in my life. I just didn't want to see, and I didn't want other people to see what I looked like when I was going through it. So I don't have any photos of me, I think the only one I have left is probably that one little one where my hair is just this little piece. –Ashley,

> age 30, dx at 12

Another participant experienced the time of her major hair loss as *not* marked as dark or lost. Her AA largely did not stop her from being involved or decrease her self-worth.

> I was pretty active in college. I started running half marathons and marathons, and I had a good group of friends. I was really involved in the college democrats. I think just going about my daily business and being able to feel like the alopecia wasn't affecting me in any way was a good day. I think most of my days were good days. I certainly don't look back and think of that time as a dark period or anything. It was harder than high school, but it doesn't have a shadow over it or anything. –Rachel, age 29, dx age 13

Changed realities/Pivotal moments. Certain experiences or moments forever changed participants' realities. For some, the onset and diagnosis of AA resulted in a major shift in their understanding of the world. Perhaps there was a realization that usual strategies for solving problems would be useless in the face of this new and unfamiliar diagnosis. One participant described this in the context of early visits with medical providers.

> I remember the interactions being so incredibly painful that it was just too much to bear. I felt very, very disheartened, and very scared and nervous. There was a lot of fear of the big unknown. I had never met anyone with alopecia. I had never heard of alopecia. I didn't really know what could happen. I remember the dermatologist implying there was really nothing I could do. And that there is medicine, but this was a life-long thing. It's something that's going to turn off. It might go to sleep, but it's never going to be fully off. I remember trying to deal with that. I was disheartened in the fact that there was nothing I could do. This was maybe my first time of really feeling or thinking, "I don't got this." My parents were so proactive, and I try to be fairly proactive. It wasn't like, "Oh, we can just go to Stanford, or we can just go to UCLA or John's Hopkins." It was, "There is no option besides the medicine." And that's just placating the problem. It's really just putting the problem on ice. It's going to come back. –Halle, age 29, dx at age 15

Alternatively, early experiences of AA felt perceptually different from the previous normal: time seemed on fast forward. The feeling of being continuously observed triggered the development of a "hyperawareness."

> I just remember not really thinking much of it until after I started seeing people. I felt like eyes were on me at all times. I just remember feeling self-conscious - and at 10 you don't even know what that is. I felt like a completely different person. All I remember was just feeling all the sudden things changed overnight. I feel like I was just much more aware of things after that. I didn't realize it, and it went from me not noticing anything to me being self-conscious and noticing *everything*. In that time span, suddenly I was hyperaware. And I guess that was my overnight, because it all happened so quickly. I feel like it was one minute she was talking to me in the bathroom and I was at all these doctors, and then it was just a flood. It all just seemed to kind of happen fast. All of a sudden I was just hyperaware of everything. I didn't feel like a little kid anymore. All of the sudden I was just nervous all the time.
> –Bella, age 27, dx at age 10

For Bella, attention engendered a reflexive self-consciousness; an awareness of her difference. It is as if noticing others' reactions to AA turns on a switch that rapidly advanced her from childlike innocence and freedom to having an adult-like burden of constant concern.

This world-changing shift did not happen for everyone early in their AA. Some did not feel they had to acknowledge the presence of AA for quite some time.

> I think maybe the reason it wasn't a big deal for me in high school is because I was sort of in denial about it. Not in a bad way. I acknowledged it, but I thought it was a temporary thing. I never thought I had to deal with it. I just sort of ignored it. I just went on with my life, and it just was. I hadn't lost enough hair at that point where I really had to deal with it.
> –Rachel, age 29, dx at age 13

Some participants later reached a point of no return in their experiences of AA in which they forever changed their approach to managing it. The day Rachel shaved her head was monumental for her; a day where she reclaimed her life surrounded by the support of her family and new mentor.

> The wig representative shaved my head. She took a measurement of my head for the wig. I think I felt relieved. It was like, this has been a long time coming. You know, even as I was doing it I never thought this was the wrong thing. I never felt like turning back or jolted or anything. It just felt right. It just was a relief. It was a big day. It was a really big day…I think that was sort of the next chapter. I was ending being the victim, and I was starting as a new me. It was over. The fight was done. The crazy thing is that I thought that I would feel like I had lost the race, but I actually felt like I had won it by shaving my head. It was pretty cool. It was pretty cool. –Rachel, age 29, dx age 13

Shaving her head was the catalyst for several changes; she went from distressed and constrained to completely freed.

> And then after my head was shaved, I was like, "Oh my God! Why didn't I do this years ago?" I'm like, "This is so much better!" It was like shedding *all* of this anxiety and all of this denial. I had just shed all of it. Instantly, all of it came off with my hair. Like shedding my snake skin or something. I was just like a new person. I was able to go off my medications. I would walk around town with no wig. I would just walk around with my baldhead. I would go to stores with my mom with my baldhead. We'd run into people we knew with my baldhead. I think I was so sick of being afraid and ashamed, that when I shaved my head I was like, "Well this is it! This is me now!" I'm not hiding it anymore. It was so liberating. My only regret through my entire process is that I wish I had done it a year or two sooner. I think I held on for a little bit too long. –Rachel, age 29, dx age 13

Shaving was like a catharsis. The loss of shame and anxiety was freeing. Afterwards, any apprehension about revealing herself was confronted directly – no going back, this was who she was now and others would have to accept that.

> I got my first Freedom Wig [which stays on through suction] in September of 2009. And in-between the period of shaving the head and getting my Freedom Wig, I had like a full lace wig that taped down to my head.

> Which, basically I had to have until they could make my Freedom Wig, which takes a few months to manufacture. So, I remember being in New York City…I was just a few months into having my new Freedom Wig. And I remember going out onto the Staten Island Ferry. I was out on a ferry, out on a boat, and it was a super windy day, it was in the winter. And I remember being like, "Oh my God. I don't have to worry about patches on my head. I don't have to worry about my taped wig falling off. I don't have to worry about any of it. I can just be free! I can be me!" And that was a pretty cool thing to think about when it hit me. I was like, "Wow, this is the first time I have really felt in a long time like I can just stand on this boat and the wind can whip through my hair and I'm not worried. I'm not worried about anything. I can just live." –Rachel, age 29, dx age 13

Her new wigs provided additional freedom from constraint. Rachel continued to appreciate her transformation.

> So I shaved my head in 2009, and it's only been positive from then on. I think it was the right decision, and I'm super happy with the decision I made. I think I'm making a really good thing out of what can be really devastating for a lot of people. I think I felt like I had kind of suffered long enough. Like I had been in denial and been sort of ashamed for however many years, 8 years, that I was slowly losing my hair, and I just was like, "Been there, done that. And it's not any fun and it's miserable. And, so this is just how it is." And it's only been a positive experience since then. I can honestly say I have not had one bad day since then, about my hair, ever. I never think, like "Oh I wish this didn't happen to me" or "I really miss my old hair." –Rachel, age 29, dx age 13

Rachel also continued to make decisions that maintain her current freedom, rather than entering back into the cycle of trying to regrow her hair.

> That was the end of that story. And even now when I go to the doctors and I tell them I have alopecia, they'll be like, "Well, are you doing anything about it?" Or I've had dermatologists be like, "Well, we can try this, we can try this." And I'm like, "Oh don't worry about it." I'm like, "It is what it is. It's not going to grow back. And I've accepted it. And I'm not going to do all these crazy things to my body to try to fix something that just is how it is now." –Rachel, age 29, dx age 13

Rachel even started contributing to others going through a similar process. She payed forward some of the support she received. She openly shared her perspective, including advice from her emotional experience and practical tips.

> I’ve definitely tried to help other young women who have it to the extent that I can. I met with a girl who is college-aged, who is very uncomfortable in her own skin. She had a Freedom Wig, but it wasn’t cut very well. She didn’t really know how to do her makeup. So I brought her a goodie bag with my favorite makeup items and the tricks of the trade, which is basically what my mentor did for me. I’m trying to pass that along. I think my alopecia maybe happened so that I can help other people who have it. And show them that it doesn’t have to ruin your life. You can lead a really happy life. I think about the choice I made to carry on my life and not ruin it, and it really could have gone either way. I think eventually I would have had to come to that decision, but I say to myself, “I could have been miserable for another two years.” Like who knows how long it could have happened? So I hope I can kind of preach the gospel to other people, “Go ahead, shave your head. It’s okay, you can let go of it.” You can move on from this. It’s not the end of the world. –Rachel, age 29, dx age 13

Sienna’s pivotal moment involved stopping treatments and investing her time instead in her new passion: the AA support group.

> When I did the research study, that’s actually when I created the support group. They didn’t have a chapter, and I was like, "Wow, I wonder if there is [sic] other people with alopecia like me? I would love to meet them and work through it together." That’s when I created the support group. I have been the support group leader for over three years now.
>
> I really don’t want to do any treatment anymore. I am just over it. Because with alopecia even if I do treatment, in my eyes it’s like, if I do treatment and my hair grows back, am I going to do this for the rest of my life? For me to put cream on my head or whatever it is every night, every day, if I had my hair back, I would rather just not have hair. Because it’s a lot to do it every single night or whatever it is, and then I can't take a shower or I have to shower, or I have to wait an hour and, it’s just like time consuming and it gets annoying. I’m not trying to be ungrateful, but it gets so annoying. I don’t know if that’s bratty of me or what? It’s just like, enough is enough. I have done so many treatments, nothing is working, and I would rather just live my way. For me, and I think for the majority of people, it’s really important to have a solid support system. I really focus on the alopecia support group. –Sienna, age 31, dx at 15

Sienna's support group developed into an additional source of support for her as well as others. Sienna reprioritized living her life unencumbered by medical treatments. As an advocate and educator for the community, she used her confidence to spread the word about AA.

> I have done this a lot where I'll be in a grocery store or in a mall. If a woman comes up to me and says, "Oh, I love how you wrap your scarf! Did you do it yourself?" I'll be like, "Yeah, I'll show you how to wrap it right now." I literally pull off the scarf and my whole bald head is exposed to this woman and whomever is around us. I don't get fazed whoever is there. I just show them how to wrap the scarf. Then I'll tell them about the alopecia. I'm like an alopecia sergeant. I feel like I'm supposed to do this every day. I'm supposed to share it. –Sienna, age 31, dx at 15

Sienna did not feel fazed by exposing her baldhead to strangers rather, she felt a sense of purpose. As an "alopecia sergeant," she diligently recruited and educated, responding to the command of her calling.

Sienna shared that her involvement as leader of the AA support group is now a major component of her day. She is "more than happy" to provide support and spend time on the phone, fulfilling her mission of providing support to others with AA.

> A lot of my day is spent on the phone with people who have alopecia. I also get phone calls from numbers that I don't recognize, who are usually people asking for information about our group and how they can get support. Usually it turns into a few hours of my day where I'm on the phone with these people, which I'm more than happy to do. And I try and give them support and give them direction and tell them about my experience with alopecia and what works for me a on daily basis to help me be positive and keep going in my life. –Sienna, age 31, dx at 15

Halle asserts that her period of lost time in her 20's, when her hair loss dramatically increased and she started wearing a wig, was also pivotal experience. Moving forward she was a changed person and feels her AA "dictates" her life.

> I think that I definitely view my life as before the wig, and after the wig. I'm now a completely different person than I was before. I was much more carefree; I was much more go-with-the-flow. And now I'm so rigid and type A. And I'm always preparing for everything because, I can't just be a person who is late for work so I'm just going to grab a sandwich for lunch. I can't do that. I don't eat gluten. I don't eat dairy. It inflames my body, which will then lead to hair loss. So, I'm cooking all the time. I'm preparing every meal. I just don't want to take that chance. My alopecia dictates every part of my life. I can't think of one part of my life it doesn't dictate. It dictates what I eat, what I don't eat. It dictates how much sleep I get. It dictates what alcohol I drink. It dictates how I wear my hair. It dictates when and where I exercise, and how I exercise. It dictates how I dress and how I wear my hair to work. It dictates how I deal with people on a daily basis. I'm always, always, always trying to eliminate as much stress as is possible. It dictates the way I use my personal time at work. It dictates everything. So the time in-between wearing a wig and when it really started, I don't remember much other than being a totally different person. –Halle, age 29, dx at 15

Individual differences in emotional experiences. Across time, participants experienced various emotional reactions that were important components of their lived experiences. As the above descriptions illustrate, the emotional experiences of AA can be somewhat idiosyncratic across participants. Helplessness often appeared when there was an awareness of pending hair loss that could not be stopped, or other situations where options were less than ideal or circumstances out of the participant's control. Distress appeared in a number of ways across various experiences. Some referred to this as "anxiety" or "devastation." Some insisted they never experience a moment without concerns related to their AA. And yet, at least one participant was never "fazed." Feeling completely alone was clearly articulated by one participant, and for her it captured what was the most painful aspect of having AA for a very long time. Losing hair could be a deep emotional loss, feeling like the death of a part of oneself. For some it was not necessarily the hair loss that brought about this emotional loss, but the act of shaving the scalp. Frustration was especially felt in social situations where people were acting rude or staring, or when the limitations or routines to manage AA became fatiguing or impactful. Relief often came with a sense of freedom: from AA itself via regrowth, or from concern about AA being discovered through wigs or other means. One participant clearly articulated her experience of relief that came with shaving her head and choosing to give up her distress. Acceptance sometimes came from others– from a partner, a family member, or a friend who continued to tell them they were beautiful or were otherwise "fine" with the revelation of AA. Acceptance also was described by some as a personal attitude about their AA, and involved no longer putting in efforts to regrow hair. For others, personal acceptance is unfathomable, because the implications of resigning to a life with AA is too painful. On the whole, AA is an emotional experience that can be very different depending on the individual and where they are in the process of living with AA. One participant shared participating in this study elucidated that fact for her.

> I guess the biggest thing I've taken away is just that it probably consumes more of my emotions than I maybe first had thought, or that I had thought prior to our first interview. And not in a bad or even a good way, just that I didn't realize it affected me that much. Because I feel I just put on my wig every day and just walk around. And I'm quote un-quote "normal." I just had never really thought about all the feelings from all the different experiences. And that it was a whole process with all sorts of different emotions that I had never really thought of before. –Gabriella, age 36, dx at 7, onset at 14

Discussion

Phenomenological analysis of in-depth interview data from six adult women with AA who developed it during or before high school drew attention to life-affecting ways AA is experienced over time. The resulting textual description revealed the complex and idiosyncratic essences of AA for these women. In the following section, major findings are discussed, followed by study limitations, practice implications, and recommendations for research.

What Is Experienced with AA?

Participants in the present study described going through multiple experiences: the initial moment of awareness of their AA, visits to doctors to receive a diagnosis, awareness of increased shedding, adopting strategies to conceal or cover AA, using medical or other treatments in efforts to regrow hair or forestall future loss, and interacting with others about their AA – verbally or non-verbally. A subset of participants also experienced regrowth and/or subsequent relapse of AA. Participants experienced a variety of psychological responses throughout their experiences of AA as well – including helplessness and distress, a sense of being completely alone, emotional loss, frustration, relief and/or acceptance. These experiences align closely with the findings of previous studies, such as Hunt and McHale's (2005a) categories of personal, medical, and social experiences. The experiences identified in the present study are also expected given the natural course of AA and how its visible nature creates a social dimension. The phenomenological method used in this study allowed participants to describe these experiences in rich and illuminating detail, especially given Van Manen's (2014) existentials.

How is AA Experienced?

Lived body. AA impacted how participants experienced their bodies across time. Initially, noticing a spot transformed a preexisting neutral view of the body or relative unawareness of its health or appearance into cause for concern. The concern might have started as a worry about health and vitality. With the diagnosis participants learned that their hair loss was not a harbinger of ill health, but a new and different appearance. The extent of this difference varied initially, and some participants continued their lives unencumbered by their AA until a later increase in hair loss. They endeavored to maintain an appearance that still looked "like me," and sometimes struggled to view their new appearance as feminine. Physical sensations associated with AA and the sight of shedding hair could be distressing, similar to adjusting to the reflection of oneself in the mirror without any hair. They might have used strategies such as wigs or hair pins to disguise the AA, sometimes providing relief that their reflection now more closely matched their self-image. Ongoing self-confidence and positive body-image throughout the changes in AA made bodily changes less psychologically impactful for some.

The findings related to lived body are similar to those of Welsh and Guy's (2009) study of body image and coping. Those authors found individuals with AA often went through a process of initially feeling distressed by the hair loss and concerned about their femininity, but for many the distress decreased over time. In the present study, however, distress was less related to duration of AA, as one participant never felt "fazed" and another participant's distress seemed to grow and increase over time. Given range of participants' emotional responses, results of the present study are both consistent with and contrary to theories of coping and adaptation to chronic illnesses. Folkman, Lazarus, Gruen, and DeLongis (1986) state that adaptation to health and physical symptoms comes about through coping processes. Specifically, recurring, uncontrollable events can trigger a downward spiral of maladaptive coping and adaptation, resulting in helplessness, passive coping strategies, demoralization, and depression. Thus, the uncertainty of hair loss and regrowth in AA might result in a similar downward cycle.

Lived relations. Onset of AA and awareness was highlighted through descriptions of interactions with others, from comments (e.g., teasing, questions about cancer) to stares and whispers. Lack of self-awareness in youth was transformed into total awareness through such interactions. This shift caused a realization that the participant was no longer a "little kid." Supportive friends and family who treated them no differently with their AA provided a sense of normality and safety. Sometimes participants felt insulted by peers or strangers, so they undertook efforts to make the AA more private including wigs, hair pins, and socially withdrawing. These findings make sense in the context of theories of social stigma and physical differences. According to Goffman's (1963) description of stigma, physical characteristics that are counter to social expectations are stigmatizing traits. Thus, because most people expect scalp hair, eyebrows, eyelashes, and facial or body hair, individuals with AA theoretically have a stigmatized identity. When they keep their AA hidden (e.g., wearing wigs), their AA becomes a concealable stigmatized identity, that is, "an identity that can be kept hidden from others but that carries with it social devaluation" (Quinn & Chaudior, 2009, p. 635). Concealable stigmatized identities create anticipated stigma and fear about what might happen should the identity be revealed (Quinn & Chaudior, 2009). Some participants in the present study described experiencing stigma, and they continued to have concern about negative reactions should their AA be identified. Alternatively, other participants chose to transition (or were in the process of doing so) to living with their AA revealed in public. Those participants found living with AA revealed could be frustrating, as strangers tended to be curious and stare or comment. The personal authenticity and comfort that comes from living without a wig was the trade-off, and educating others about AA used as a way to minimize negative social responses.

Similar to Wiggins et al.'s (2014) findings, some of the present participants described the dilemma of disclosing hidden AA. They may feel a desire to disclose to obtain support, but their desire is offset by uncertainty regarding how someone might respond. The actual moment of revelation was for some, highly uncomfortable, and especially so when they felt they did not have a choice but to disclose. Other participants felt completely comfortable disclosing and made frequent disclosures of their AA a regular part of their life. Some women continued to feel concerned about incidental disclosure, that is, by their wig being noticed or falling off. Similarly, participants in Welsh and Guy's (2009) study described awareness that their appearance would be noticed, and they expressed concerns about stigma and rejection. Some thus withdrew from social interactions and questioned whether they could ever have "normal" interactions again (p. 196). Their social withdrawal, however, was limited to the short term after initial onset, and over time "most participants found their condition was not as limiting as they had perhaps initially feared" (p. 197). Similarly, participants' in the present study might have withdrawn socially after initial onset or worsening, but they did not seem to withdraw over time. Instead, they lost their discomfort with AA, identified strategies that provided comfort (e.g., better wigs), or entered social situations regardless of feeling uncomfortable.

Lived space. AA is experienced in a variety of spaces. It often first began in the bathroom, a shower or in front of a mirror. Some participants eventually avoided the shower or other spaces for temporary relief from the painful awareness of increased loss. AA is experienced at clinics, which might communicate seriousness and concern. AA was also experienced at home, which often provided freedom and comfort. Alternatively, one participant felt rejected at home because her rapidly progressing hair loss was not welcomed in certain spaces. AA and associated approaches to its management also limited participants' freedom to comfortably experience certain settings: swimming pools, outdoors in the wind or rain, or – in one case – the kitchen where a family comes together to bond. Settings in which a participant experienced bullying – a school, for example – were changed previously safe spaces to unsafe ones. Differential experiences of AA according to space seem to be a novel way of thinking about the experience of AA. These findings make sense given the aforementioned social dynamics vary according to spaces and situations.

Lived time. Lived time was an especially noteworthy aspect of AA experiences. Two major themes emerged in the present study: lost time and dark periods, and changed realities/pivotal moments. These themes highlight dramatic shifts that were especially memorable and impactful for some participants. The temporal nature of these themes has important implications. Because lost time and dark periods are memorable spans of time with discrete ends and beginnings, these periods of greater distress or depression were time-limited. Their temporal nature makes sense as time provides opportunities to adjust to new circumstances, find social support, and/or have sporadic hair regrowth. Welsh and Guy (2009) also found participants experienced less distress as they adjusted to their AA and its uncertainty.

The theme of changed realities and pivotal moments in the present study revealed major shifts in which a participant reached a point where her understanding of the world or her approach to living with AA was completely transformed. Changed realities seemed to represent a shift from innocence and unawareness, to greater awareness of one's difference from others and/or newfound lack of control. These realizations forced participants to feel as though they had to grow up quickly, and is a theme similarly found in research on children with chronic diseases (cf. Sullivan, 2004). The pivotal moments also represented a new reality, but often one in which participants had a choice. For instance, this change manifested as choosing to put less energy into medical treatments and strategies for concealing AA, choosing to be more involved in the AA community, or being moved by the uncertainty of AA to focus one's entire life around efforts to prevent future loss. They represent a tipping point that illustrates how change can come about in AA. Such a turning point has been documented as an experience for individuals with chronic disabilities (cf. King et al., 2003).

Study Strengths and Limitations

The present study presents a novel approach to understanding AA, richly revealing the experiences of AA. The methodology was carefully guided by philosophical assumptions and research paradigms, and the lengthy interviews allowed the investigator to obtain in-depth data regarding the women's experiences with AA. While individuals who subscribe to email lists or social media accounts of AA support groups might not adequately represent the experience of AA for all individuals, this is not a major concern for the present study given the methodology and relativist belief that multiple realities exist. Thus, the aim of the present study was not to present a generalizable compendium of all experiences, but to present some examples of potential experiences with AA. The present sample was adequate to achieve that goal, and the clear variability of participants' responses also shows recruitment through AA foundations and support groups might be a useful way to engage participants with diverse experiences. The use of anecdotes constructed from the women's descriptions presents another potential limitation, but this approach is again consistent with the phenomenological methodology where the goal is eliciting understanding through language rather than empirical factuality. In addition, participants' responses to their individual results suggested the anecdotes and analyses were relatively consistent in maintaining the meaning of their original descriptions.

Importantly, the present study did not capture certain information about the AA population that may be particularly useful for psychological practitioners. For instance, the study did not directly assess mental health diagnoses, or needs and preferences of individuals for psychological services. The present research is important, however, as it serves as the first study representing a strong description of the psychological phenomenon of the lived experience of AA without having a pre-determined emphasis on coping and using Van Manen's (1990, 2014) methodological approach.

Practice and Training Implications

The rich description of the experience of AA for women ages 30-35 who have had

AA since at least high school has important potential significance for practitioners. For instance, providers including psychologists, dermatologists, and other helping professionals might better understand the essential experiences of AA and their meaning, and thus be able to better empathize with individuals seeking their help and support. Given participants' emotional experience of AA in the present study were so diverse, it seems clear that a brief assessment of an individual's personal reactions to AA is needed before making assumptions about needs for services or the presence or absence of mental health concerns. In addition, mental health professionals working with individuals who have AA may be better able to validate clients' experiences and explain how there is no typical emotional response to AA. The process of coming to acceptance of AA, for some participants, suggests an acceptance-based therapeutic approach, such as Acceptance and Commitment Therapy, might be useful.

Research Recommendations

Results of the present study identify experiences that can be the target of later qualitative and quantitative research. For instance, many of the participants described only temporary mental health concerns, if any at all, suggesting studies focusing solely on psychopathology are missing a great deal of the aspects of living with AA. Research in this area might be advanced by the implementation of more studies on positive coping, social support and interactions, and/or the process of coming to acceptance of AA. Given the present sample is homogeneous with respect to age, gender, educational background, and race/ethnicity, the present study could be replicated and extended by investigating the lived experience of AA for individuals who are more diverse demographically. In addition, qualitative studies might further explore the novel findings relating to how living through AA over time involves noteworthy moments, pivotal changes, and new realities. They might also investigate how AA is experienced differently in particular spaces.

Conclusions

Alopecia areata impacts early adult women’s lives in a variety of ways, which can differ across time as well as across situations and relationships. AA can produce a great deal of distress that persists after more than a decade of living with it. For others, AA is less distressing. Psychologists and other providers might best serve individuals with AA by assessing their individual experiences of AA and meeting them “where they are at.” Future research might investigate the process of how some individuals with AA come to greater acceptance or appreciation for their AA, as was experienced by some participants in the present study.

Bibliography

Bemmels, H. (2015). *Alopecia areata: Just how psychosocially debilitating is it*? (Unpublished oral preliminary exam paper). University of Minnesota, Minneapolis, MN.

Carr, T., Harris, D., & James, C. (2000). The Derriford Appearance Scale (DAS-59): A new scale to measure individual responses to living with problems of appearance. *British Journal of Health Psychology, 5*(2), 201-215.

Cartwright, T., Endean, N., & Porter, A. (2009). Illness perceptions, coping and quality of life in patients with alopecia. *British Journal of Dermatology, 160,* 1034-1039.

Cash, T. F., Santos, M. T., & Williams, E. F. (2005). Coping with body-image threats and challenges: Validation of the Body Image Coping Strategies Inventory. *Journal of psychosomatic research, 58*(2), 190-199. doi:10.1016/j.jpsychores.2004.07.008

Folkman, S., Lazarus, R. S., Gruen, R. J., & DeLongis, A. (1986). Appraisal, coping, health status, and psychological symptoms. *Journal of Personality and Social Psychology, 50*(3), 571-579.

Gilhar, A., Etzioni, A., & Paus, R. (2012) Alopecia Areata. *New England Journal of Medicine, 366,* 1515-1525.

Goffman, A. (1959). *The presentation of self in everyday life.* Garden City, NY: Doubleday, Anchor Books.

Goffman, A. (1963). *Stigma: Notes on the management of spoiled identity.* New York: Simon and Schuster.

Goffman, A. (1972). *Interaction rituals: Essays on face-to-face behavior.* London:

Penguin.

Gupta, M. A., Gupta, A. K., & Watteel, G. N. (1997). Stress and alopecia areata: A psychodermatologic study. *Acta Dermato-Venereologica, 77*(4), 296-298.

Hordinsky, M., & Donati, A. (2014). Alopecia areata: An evidence-based treatment update. *American Journal of Clinical Dermatology, 15,* 231-246. doi:10.1007//s40257-014-0086-4

Hunt, N., & McHale, S. (2005a). Reported experiences of persons with alopecia areata. *Journal of Loss and Trauma, 10,* 33-50. doi: 10.1080/15325020490890633

Hunt, N. & McHale, S. (2005b). The psychological impact of alopecia. *BMJ: British Medical Journal, 331*, 951-953. http://dx.doi.org/10.1136/bmj.331.7522.951

King, G., Cathers, T., Brown, E., Specht, J. A., Willoughby, C., Miller Polgar, J., … Havens, L. (2003). Turning points and protective processes in the lives of persons with chronic disabilities. *Qualitative Health Research, 13*(2), 184-206. doi:10.1177/1049732302239598

Liu, L. Y., King, B. A., & Craiglow, B. G. (2016). Health-related quality of life (HRQoL) among patients with alopecia areata (AA): A systematic review. *Journal of the American Academy of Dermatology, 75*(4), 806-812. doi:10.1016/j.jaad.2016.04.035

Matzer, F., Egger, J. W., & Kopera, D. (2011). Psychosocial stress and coping in alopecia areata: A questionnaire survey and qualitative study among 45 patients. *Acta Dermato-Venereologica, 91,* 318-327.

Mirzoyev, S. A., Schrum, A. G., Davis, M. D. P., & Torgerson, R. R. (2014). Lifetime incidence risk of alopecia areata estimated at 2.1 percent by Rochester Epidemiology Project, 1990–2009. *Journal of Investigative Dermatology, 134*(4), 1141–1142. doi:10.1038/jid.2013.464.

Olsen, E. A. (2011). Investigative guidelines for alopecia areata. *Dermatologic Therapy, 24,* 311-319.

Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology, 52*(2), 126-136. doi:10.1037/0022-0167.52.2.126

Quinn, D. M., & Chaudior, S. R. (2009). Living with a concealable stigmatized identity: The impact of anticipated stigma, centrality, salience, and cultural stigma on psychological distress and health. *Journal of Personality and Social Psychology, 97*(4), 634-651. doi:10.1037/a0015815

Rafique, R., & Hunt, N. (2015). Experiences and coping behaviors of adolescents in Pakistan with alopecia areata: An interpretive phenomenological analysis. *International Journal of Qualitative Studies on Health and Well-being, 10,* 206039. doi:10.3402/qhw.v10.26039

Rencz, F., Gulácsi, L., Penték, M., Wikonkál, N., Baji, P., & Brodszky, V. (2016). Alopecia areata and health-related quality of life: A systematic review and meta-analysis. *British Journal of Dermatology, 175,* 561-571. doi:10.1111/bjd.14497

Seidman, I. (2012). *Interviewing as qualitative research: A guide for researchers in education and the social sciences.* (4th ed.). New York, NY: Teachers College Press.

Sullivan, N. A. (2004). *Walking with a shadow: Surviving childhood leukemia.* Westport, CT: Praeger Publishers.

Tucker, P. (2009). Bald is beautiful?: The psychosocial impact of alopecia areata. *Journal of Health Psychology, 14,* 142-151. doi:10.1177/1359105308097954

Van Manen, M. (1990). *Researching the lived experience: Human science for an action sensitive pedagogy.* Albany, NY: State University of New York Press.

Van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing.* Walnut Creek, CA: Left Coast Press, Inc.

Venes, D. (Ed.). (2013). Taber's cyclopedic medical dictionary (22nd. ed.). Philadelphia, PA: F. A. Davis Company.

Welsh, N., & Guy, A. (2009). The lived experience of alopecia areata: A qualitative study. *Body Image, 6,* 194-200. doi:10.1016/j.bodyim.2009.03.004

Wertz, F. J. (2005). Phenomenological research methods for counseling psychology. *Journal of Counseling Psychology, 52*(2), 167-177. doi: 10.1037/0022-0167.52.2.167

Wertz, F. J. (2011). A phenomenological psychological approach to trauma and resilience (pp. 124-164). In F. J. Wertz, K. Charmaz, L. M. McMullen, R. Josselson, R. Anderson, & E. McSpadden (Eds.), *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry.* New York: The Guilford Press.

Wiggins, S., Moore-Millar, K., & Thompson, A. (2014). Can you pull it off? Appearance modifying behaviours adopted by wig users with alopecia in social interactions. *Body Image, 11,* 156-166. doi:10.1016/j.bodyim.2014.01.004

Appendix A

Review of Literature and Rationale for the Present Study

Extant literature is limited in its ability to inform psychologists about the psychosocial effects of AA. The majority of published studies involve quantitative methods and focus on measuring general psychopathology and mental health symptoms (e.g., Hunt and McHale, 2005b; Tucker, 2009), personality disorders or traits (e.g., Annagur, Bilgic, Simsek, & Guler, 2013; Cordan Yazici et al., 2006), stress responses (e.g., Gupta et al., 1997; Monselise et al., 2013), or quality of life (QOL; e.g., Liu, King, & Craiglow, 2016; Rencz et al., 2016). Fewer quantitative studies also measure coping styles (e.g., Cartwright et al., 2009; Matzer, Egger, & Kopera, 2011), illness perceptions or attitudes (Cartwright et al., 2009; Invernizzi et al., 1987; Ruiz-Doblado, Carrizosa, & Garcia-Hernandez, 2003), social support (Picardi et al. 2003; Tkalčić, Dragojević, & Brajac, 2001), family environment (Diaz-Atienza & Gurpegui, 2011), attachment (Picardi et al. 2003), body concept (Matzer et al., 2011), and/or self-esteem (Tkalčić et al., 2001). Those quantitative studies neglect the deeper aspects of individuals' experiences, such as the what individuals experience in relation to their AA that might precipitate mental and emotional difficulties. In addition, by focusing on the adversity of living with AA, researchers neglect neutral and/or positive ways AA might be experienced. A qualitative approach is helpful for addressing those limitations.

A few researchers have used qualitative methods to investigate the experience of AA. Many qualitative approaches are available to researchers, and each approach is appropriate for particular types of research questions or objectives. For example, grounded theory is most appropriate for developing an explanatory theory rather than describing an experience (Creswell, 2013). Two published studies in AA involve grounded theory methods (Hunt & McHale, 2005a; Matzer et al., 2011). Phenomenological methodology, on the other hand, allows a research to deeply understand the meaning of individuals' lived experiences with a phenomenon (Hays & Wood, 2011). The outcome of such research is a detailed description of the psychological experience of a phenomenon, rather than a theory or hypothesis (Giorgi, 2009). Two studies involve a phenomenological approach referred to as Interpretive Phenomenological Analysis (IPA; Welsh & Guy, 2009; Rafique & Hunt, 2015). Other studies use semi-autobiographical (Beard, 1986), case study, (Grahovac, Ružic, Šepić-Grahovac, Dadíc-Hero, & Pavešić Radonja, 2010), or discursive psychology (Wiggins, Moore-Millar, & Thompson, 2014) approaches.

Qualitative studies in AA are informative about the experience of AA; however, there are some limitations. For instance, many studies appear to target a particular topic, potentially directing participants to describe certain types of experiences. Hunt and McHale (2005a) indicated they used a non-biased qualitative approach, but their directions asked participants to describe "issues relating to their alopecia" (p. 35). They represent the only qualitative study to report, "very few accounts that indicated positive adaptation, and successful coping" (Hunt & McHale, 2005a, p. 40) despite having quite a large sample size (N = 196) for a qualitative study. Matzer et al. (2011), Rafique and Hunt (2015), and Welsh and Guy (2009) all identified a purpose of their projects was to better understand coping behaviors. Not surprisingly, those studies resulted in detailed descriptions of coping with AA. Wiggins et al. (2014) focused even more specifically on social experiences including appearance-modifying behaviors. Clearly, the interview questions researchers employ can influence participants' responses in qualitative research studies. Holistic, open-ended research is needed to appreciate the experiences of AA.

In addition to the language used in questions, the methods of data collection may impact the depth of responses. Qualitative research requires delineation of a theoretical framework (Creswell, 2013). The phenomenological method is most commonly described as being consistent with the constructivist-interpretivist point of view, in which multiple realities exist and the researchers endeavor to understand them (Ponterotto, 2005). In such research, knowledge is gained through "intense" interactions and "close prolonged interpersonal contact" with the participant (Ponterotto, 2005, p. 131). Seidman (2013), for instance, recommends phenomenological researchers complete a series of three 90-minute interviews with each participant. Qualitative research on AA has used various methods of data collection, including brief written descriptions and open-ended responses to email survey questions (Hunt & McHale, 2005a), and interviews of various lengths (*M* = 44 minutes, *range* = 20-84, Matzer et al., 2011). Wiggins et al.'s (2014) study employed the most extensive data collection approaches, including focus groups, two 2.5 hour interviews, and video diaries ranging in length from 18 min. to 4 hours. Importantly, the authors of both phenomenological studies reported completing onetime interviews typically lasting one hour or less (*M* = 45 min., Rafique and Hunt, 2015; *range* = 30-60 min., Welsh & Guy, 2009). Phenomenological research might uncover additional details with more extensive interaction between the interviewer and interviewees.

The homogeneity of sample characteristics is another important consideration in qualitative research. It is important for phenomenological research to involve homogeneous samples, or samples that are large enough to appreciate variations of the structure of the phenomenon related to variables on which participants are dissimilar. Members of an overly heterogeneous sample might have distinct experiences, making it more difficult to capture the essence of the experience of AA. Some potentially important ways a sample may differ include diagnosis, gender, age of onset of AA, duration of AA, and severity.

While there are likely similarities in experiences of individuals with differing kinds of hair loss, it is arguably important that all members of the sample have AA rather than a combination of hair loss disorders. The sporadic and sometimes relapsing course of AA and its associated uncertainty are relatively unique, as is the potential to lose all scalp and body hair (Olsen, 2011). Rafique and Hunt (2015) and Welsh and Guy (2009) agree this is an important consideration, both stating they excluded individuals with other alopecias such as pattern baldness or chemotherapy-induced alopecia from their studies because progress in those diseases tends to be more predictable. Unfortunately, not all qualitative studies have clearly described their samples. Wiggins et al. (2014) and Hunt and McHale (2005a) stated only that participants have “alopecia,” not explicitly specifying whether the sample was limited to AA only. A study focused exclusively on AA could better clarify the essence of AA-related experiences in particular.

Of studies that focused specifically on AA, each has taken different approaches to including, excluding, or describing certain participant characteristics. AA occurs with a similar frequency in both men and women (Mirzoyev et al., 2014), but it is possible their experiences may be different in key areas. Gender thus represents an area in which limiting homogeneity may be useful. No qualitative studies have investigated AA in a male-only study, and few studies are limited to samples of only women (Grahovac et al., 2010). In an unpublished dissertation, Dua's (2013) female-only sample showed participants with various forms of transient alopecia described feeling that their hair loss impacted their ability meet social ideals of femininity. Such a finding might be hidden in a mixed-gender sample, as social ideals may be different for men. Some qualitative studies of alopecia have addressed gender by including samples of male and female participants, and analyzing the data for gender differences (e.g., Hunt & McHale, 2005a; Rafique & Hunt, 2015). Such an approach favors breadth of description over depth. Importantly, recruitment of a female-only sample may also present fewer difficulties than recruitment of male participants. Most AA-specific qualitative studies with mixed genders recruited larger samples of female than male participants (n = 10 males, n = 35 females, Matzer et al., 2011; n = 3 males, n = 5 females, Rafique & Hunt, 2015; n = 4 males, n = 7 females, Welsh & Guy, 2009). An unpublished dissertation described important struggles with recruitment for qualitative research in AA, given concerns about discussing such an intimate topic (Dua, 2013). Not only will a study focused on a sample of only female participants address an important need; it would likely be more feasible as well.

Some studies have not specified extent or severity of hair loss (Rafique & Hunt, 2015; Wolf, 2015). All studies that reported extent of AA used heterogeneous samples, including participants with limited or patchy AA in addition to AT or AU (Matzer et al. 2011; Welsh & Guy, 2009). Research may support this approach, as severity of AA may not act as expected. For instance, Reid et al. (2012) compared self-rated and formalized physician-rated severity of alopecia, and found participants perceived their hair loss as significantly more severe than their dermatologists ($p < 0.0001$). While Matzer et al. (2011) did not specify their methods for determining severity, they reported results suggesting severity of AA does not impact perceived burden of the condition. Hunt and McHale (2005a) likely used self-rated severity given their correspondence with participants was through the mail or email. They reported results showed participants with less severe alopecia described a greater severity of symptoms, but not different kinds of symptoms than those with a more severe form of AA. Taken together, these studies provide little guidance on how AA severity is best classified, and whether it should be limited in a psychosocial research study. Guidance about other variables is clearer and more substantial.

The age range of participants may also be important. Although the onset of AA can occur at any age, roughly 80% of individuals who have AA are less than 40 years of age (Gilhar et al., 2012). Studies of AA take various approaches regarding age. Most qualitative studies limited their samples to adults (Beard, 1986; Matzer et al., 2011; Welsh & Guy, 2009) or adolescents (Rafique & Hunt, 2015), perhaps because their cognitive capacity for describing experiences is typically greater than in childhood. Samples of adult participants also allow for a potentially longer duration of being affected. Developmental theories that partition the lifespan into discrete stages according to chronological age are controversial (Settersten, 2007). Early adulthood traditionally ranged from after adolescence to age 40, and typically included important transitions relating to a woman’s career and family (Roberts & Newton, 1987). The age ranges associated with early adulthood have shifted somewhat upward in modern society, with many individuals waiting until later to start their careers and families (Settersten, 2007). It would be educative to understand the meaning of AA in modern early adulthood, a time when women are making decisions associated with important milestones. Research with a narrowly homogeneous sample of women in early adulthood, such as ages 30-35, would provide such a description.

The phenomenological studies of AA have taken duration into account, and suggest it may be an important characteristic. For instance, Welsh and Guy (2009) rationalized “it was essential that participants had received a formal diagnosis of alopecia for a minimum of 6 months in order to explore the ‘lived experiences’ of the condition” (p. 195). Participants’ durations of AA in their study varied widely from 2 to 49 years. Their results showed participants underwent a process of coping with AA over time, which suggests individuals who were very recently diagnosed with AA may have distinctly different experiences of AA than those who with experiences across several years or decades. Rafique and Hunt (2015) similarly required participants to have visible AA for at least a year “to allow enough time for living with the experience of alopecia” (p. 3). They set a cut point for a maximum length of AA as well, limiting participants to duration of no more than 3 years and, thus, producing a more homogeneous sample. Duration may be an important consideration in designing a qualitative study of AA.

No qualitative studies of AA in adults have established a narrowly specified range for the age of onset. An interesting approach to understanding the phenomenon of AA over time, and also enabling a more homogeneous sample, would be to pre-establish specific criteria. Heary, Hennessy, and Swords (2014) consider childhood and adolescence critical developmental periods for establishing personal sense of self as well as bonds with others. They warn that stigmatizing “social responses” regarding a youth’s disability, chronic health condition, or visible difference may result in “potentially deleterious effects” (Heary et al., 2014, p. 205). It would be informative for a phenomenological study to include a sample that is able to retrospectively speak to the experiences of having AA during one of these key developmental stages. While there can be concerns with long-term recall, a sample of adults who developed AA in their youth could allow for rich description of experiences across one of these stages. It would lend context to their personal stories, something Seideman (2013) asserts requires its own interview to fully appreciate. Limiting the sample to only women who developed AA as adolescents would improve homogeneity, and potentially result in richer data as the ability to think abstractly about experiences is greater in adolescence as compared to earlier ages.

Understanding the long-term impact on females developing AA during adolescence would also be interesting as some researchers argue that period of life may predispose individuals to experience “storm and stress” (Hollenstein & Lougheed, 2013, p. 444). Dermatology research across diseases has shown emotional experiences may be especially acute during adolescence, as Gupta and Gupta (1998) found greater suicidality in adolescents with severe acne than populations with other dermatological conditions (including AA) in which the age range varied. Rafique and Hunt's (2015) phenomenological study specifically investigated Pakistani adolescents' experiences with AA. One of the major themes uncovered by Rafique and Hunt is concerns and fears. It would be interesting to see how women with AA continued to manage such fears and concerns over time, such as the "fear of not being able to fall in love or get married" (p. 10). Women in early adulthood could say more about whether such concerns have endured or faded.

Conclusion

A gap exists in the literature regarding qualitative, phenomenological research for women with a specified age range and duration of AA. Such a study would provide important details about how AA is experienced across critical life experiences and social interactions. An approach that minimizes bias, especially regarding coping with AA, is needed to further clarify the experiences of AA over time.

References

Annagur, B. B., Bilgic, O., Simsek, K. K. & Guler, O. (2013) Temperament-character profiles in patients with alopecia areata. *Klink Psikofarmakoloji Bulteni-Bulletin of Clinical Psychopharmacology, 23*(4), 326-34. doi:10.5455/bcp.20130227031949

Beard, H. O. (1986). Social and psychological implications of alopecia areata. *Journal of the American Acadamey of Dermatology, 14*(4), 697-700.

Cartwright, T., Endean, N., & Porter, A. (2009). Illness perceptions, coping and quality of life in patients with alopecia. *British Journal of Dermatology, 160,* 1034-1039.

Cordan Yazici, A., Basterzi, A., Tot Acar, S., Usatunsoy, D., Ikizoglu, G., Demirsren, D., & Kanik, A. (2006). Alopecia areata and alexithymia. *Turk Psikiyatri Dergisi, 17*(2), 101-106.

Díaz -Atienza, F., & Gurpegui, M. (2011). Environmental stress but not subjective distress in children or adolescents with alopecia areata. *Journal of Psychosomatic Research, 71,* 102-107. doi:10.1016/j.jpsychores.2011.01.007

Dua, P. (2013). “Petals falling off a rose”: The effect of hair loss on women’s identity performances. *Dissertation Abstracts International Section A: Humanities and Social Sciences, 74*(4-A(E)), No Pagination Specified.

Gilhar, A., Etzioni, A., & Paus, R. (2012) Alopecia Areata. *New England Journal of Medicine, 366,* 1515-1525.

Giorgi, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach.* Pittsburgh, PA: Duquesne University Press.

Grahovac, T., Ružic, K., Šepić-Grahovac, D., Dadíc-Hero, E., and Pavešić Radonja, A. (2010). Depressive disorder and alopecia. *Psychiatria Danubina, 22*(2), 293-295.

Gupta, M. A., & Gupta, K. A. (1998). Depression and suicidal ideation in dermatology patients with acne, alopecia areata, atopic dermatitis and psoriasis. *British Journal of Dermatology, 139,* 846–850.

Gupta, M. A., Gupta, A. K., & Watteel, G. N. (1997). Stress and alopecia areata: A psychodermatologic study. *Acta Dermato-Venereologica, 77*(4), 296-298.

Heary, C., Hennessy, E., and Swords, L. (2014). Stigma associated with disease and disability during childhood and adolescence: A developmental approach. In P. W. Corrigan (Ed.), *The stigma of disease and disability: Understanding causes and overcoming injustices* (pp. 205-222). Washington, DC: American Psychological Association. doi:10.1037/14297-011

Hollenstein, T., & Lougheed, J. P. (2013). Beyond storm and stress: Typicality, transactions, timing, and temperament to account for adolescent change. *American Psychologist, 68*(6), 444-452. doi:10.1037/a0033586

Hunt, N., & McHale, S. (2005a). Reported experiences of persons with alopecia areata. *Journal of Loss and Trauma*, *10,* 33-50. doi: 10.1080/15325020490890633

Hunt, N. & McHale, S. (2005b). The psychological impact of alopecia. *BMJ: British Medical Journal, 331,* 951-953. http://dx.doi.org/10.1136/bmj.331.7522.951

Invernizzi, G., Gala, C., Russo, R., Polenghi, M., Manca, G., & Conte, G. (1987). Life events and personality factors in patients with alopecia areata. *Medical Science Research*, *15*(17-20), 1219-1220.

Liu, L. Y., King, B. A., & Craiglow, B. G. (2016). Health-related quality of life (HRQoL) among patients with alopecia areata (AA): A systematic review. *Journal of the American Academy of Dermatology, 75*(4), 806-812. doi:10.1016/j.jaad.2016.04.035

Matzer, F., Egger, J. W., & Kopera, D. (2011). Psychosocial stress and coping in alopecia areata: A questionnaire survey and qualitative study among 45 patients. *Acta Dermato-Venereologica, 91,* 318-327.

Mirzoyev, S. A., Schrum, A. G., Davis, M. D. P., & Torgerson, R. R. (2014). Lifetime incidence risk of alopecia areata estimated at 2.1 percent by Rochester Epidemiology Project, 1990–2009. *Journal of Investigative Dermatology, 134*(4), 1141–1142. doi:10.1038/jid.2013.464.

Monselise, A., Bar-On, R., Chan, L., Leibushor, N., McElwee, K., & Shapiro, J. (2013). Examining the relationship between alopecia areata, androgenetic alopecia, and emotional intelligence. *Journal of Cutaneous Medicine and Surgery, 17*(1), 46-51. doi:10.1016/j.jaad.2010.11.042.

Picardi, A., Pasquini, P., Cattaruzza, M. S., Gaetano, P., Baliva, G., Melchi, C. F., … Biondi, M. (2003). Psychosomatic factors in first-onset alopecia areata. *Psychosomatics: Journal of Consultation and Liaison Psychiatry, 44*, 374-381. doi:10.1176/appi.psy.44.5.374

Rafique, R., & Hunt, N. (2015). Experiences and coping behaviors of adolescents in Pakistan with alopecia areata: An interpretive phenomenological analysis. *International Journal of Qualitative Studies on Health and Well-being, 10,* 206039. doi:10.3402/qhw.v10.26039

Reid, E. E., Haley, A. C., Borovicka, J. H., Rademaker, A., West, D. P., Colavincenzo, M., & Wickless, H. (2012). Clinical severity does not reliably predict quality of life in women with alopecia areata, telogen effluvium, or androgenic alopecia. *Journal of the American Academy of Dermatology, 66,* e97-102.

Rencz, F., Gulácsi, L., Penték, M., Wikonkál, N., Baji, P., & Brodszky, V. (2016). Alopecia areata and health-related quality of life: A systematic review and meta-analysis. *British Journal of Dermatology, 175,* 561-571. doi:10.1111/bjd.14497

Roberts, P., & Newton, P. M. (1987). Levinsonian studies of women's adult development. *Psychology and Aging, 2*(2), 154-163.

Ruiz-Doblado, S., Carrizosa, A., & Garcia-Hernandez, N. J. (2003). Alopecia areata: Psychiatric comorbidity and adjustment to illness. *The International Society of Dermatology, 42,* 434-437.

Seidman, I. (2013). *Interviewing as qualitative research: A guide for researchers in education and the social sciences* (4th ed.). New York, NY: Teachers College Press.

Settersten, R. A. (2007). The new landscape of adult life: Road maps, signposts, and speed lines. *Research in Human Development, 4*(3-4), 239-252.

Tkalčić, M., Dragojević, D. M., & Brajac, I. (2001). Psychoneuroimmunological perspective of alopecia areata: A preliminary report. *Studia Psychologica, 43,* 274-285.

Tucker, P. (2009). Bald is beautiful?: The psychosocial impact of alopecia areata. *Journal of Health Psychology, 14,* 142-151. doi:10.1177/1359105308097954

Welsh, N., & Guy, A. (2009). The lived experience of alopecia areata: A qualitative study. *Body Image, 6,* 194-200. doi:10.1016/j.bodyim.2009.03.004

Wiggins, S., Moore-Millar, K., & Thompson, A. (2014). Can you pull it off? Appearance modifying behaviours adopted by wig users with alopecia in social interactions. *Body Image, 11,* 156-166. doi:10.1016/j.bodyim.2014.01.004

Appendix B

Supplementary Methods & Definitions

Research Design & Philosophical Assumptions

Research paradigms (also known as interpretive frameworks) are a set of philosophical assumptions that dictate the types of questions a research project might pose, and the methods appropriate for investigating those questions (Creswell, 2013). Choosing a research paradigm is essential to designing a study that appropriately addresses its aims and objectives (Ponterotto, 2005). This is especially true for qualitative research, as the research paradigm and philosophical assumptions may vary significantly based on the author's chosen approach. As mentioned in the introduction, the present study ascribes to the constructivist-interpretivist paradigm, wherein the phenomena are constructed by individuals in their mind (Ponterotto, 2005) and brought to awareness through language (Van Manen, 2014).

The present study also uses the relativist foundational ontological belief, which Ponterotto (2005) explains is consistent with the constructivist-interpretivist paradigm and phenomenological methodology. In the relativist position, multiple socially constructed realties exist, meaning that there may be multiple valid interpretations of the data (Ponterotto, 2005). Consensus procedures are therefore not a component of the method because of the assumption that what is presented here is just one potential set of interpretations. There is no singular truth to uncover. Further, each experienced described by participants is viewed from the relativist position as merely a possible example of what it is like to experience a particular phenomenon (Van Manen, 2014). Thus, the end goal of the study is not saturation of data and repetition of themes, nor is it creating generalizability to other individuals or groups with AA. These factors are taken into account in designing the study, including the low sample size and the recognition that a theme need not be seen across multiple participants. Rather, themes are recognized because of their ability to elucidate the psychological experience for a given individual at a particular time.

Participants

Recruitment. The investigator recruited through the following ways: (1) email to approximately 390 individuals on a local Midwest NAAF support group listserv, (2) email to approximately 18,000 individuals on the national NAAF listserv, and (3) advertisements posted to the national NAAF website (NAAF.org), and Facebook (18,453 total page likes) and Twitter (3,852 followers) accounts. Twenty-nine individuals responded by email. Each participant received mailed or emailed consent forms prior to the first interview, and this investigator obtained informed consent before commencing data collection.

Data Collection

The interview guide (Appendix C) was designed to be completed in two interviews. The content of the first interview included the participants' initial experiences with AA, while the second interview covered participants' day-to-day experience of alopecia areata at the present time. The second interview also included questions related to participants' perceived meaning of their experiences. Some participants covered the topics of interviews 1 and 2 within a single interview ($n = 2$). The modal time between interviews 1 and 2, for participants who did them separately, was 3 weeks. In cases with two separate interviews, first interviews tended to be longer (*M* = 84.36, *SD* = 9.43, range = 71-91) than second interviews (*M* = 56.13, *SD* = 37.04, range = 17-93).

Data Analysis

The use of a tailored, hybrid approach – as is done in this study – is supported by Van Manen (2014) who states that a phenomenological researcher should, “seek or invent an approach that might fit most appropriately the phenomenological topic under study” (p. 226). He recommends that an author get involved in, “trying out different forms of writing and different ways of organizing the phenomenological text” (p. 227).

Bracketing and reflexivity. Subjectivity represents the influence of the researcher’s perspectives and biases (Morrow, 2005). In the proposed study, subjectivity will be viewed through the lens of constructivist-interpretivist and phenomenological approaches. These approaches recognize that the influence of the researcher cannot be separated from the research processes, and knowledge is co-constructed between the researcher and participant (Morrow, 2005; Wertz, 2005). However, phenomenology is also supposed to be a “fresh and unbiased description of the subject matter” (Wertz, 2005, p. 167). As these two positions are opposing on some accounts, phenomenological theorists advocate the use of reflexivity and epochés.

In the present study, the investigator completed a brief self-reflective narrative about her values and potential assumptions prior to begin the research process. During transcription and other data preparation stages, the investigator documented her questions and reactions in the text. These and additional reflections were added as comments aside of the text of the detailed individual analyses, and were selectively reviewed by the auditor of the data analyses.

Preparing the data. ***Anecdotes.*** According to Van Manen, re-writing participants' descriptions as anecdotes is methodologically sound because "empirical generalization is not the aim of phenomenological research… the anecdote is to be valued for other than its factual-empirical or factual-historical reasons" (p. 250-251). Instead, anecdotes are a preferred means of presenting data because, "Stories or anecdotes are so powerful, so effective, and so consequential in that they can explain things that resist straightforward explanation or conceptualization" (p. 251). Thus, using anecdotes fits the aim of the study to create understanding for the experience of AA.

The present study used Van Manen's (2014) multi-step process for transforming the data into anecdotes. Data describing opinions or the experiences of others (e.g., parents, others with AA) were omitted because they do not elucidate the participants' experiences. The remaining descriptions of events and other psychological experiences were shortened to keep the story simple. Shortening was done by removing redundancies and fillers, as well as other statements not pertaining to a given topic or the participants' experience. The anecdotes were often composed of more than one quote, thus, if a participant described the same experience in interview 1 and 2, those descriptions might be combined to provide a richer description of the details of the experience.

Phenomenological writing. The primary method of analysis in the present study is phenomenological writing, a process in which the investigator writes and re-writes about the phenomena using deep reflection (Van Manen, 2014). Per Van Manen (2016), this stage of analysis is primarily carried out by deeply wondering about the meanings of participants' experiences. He emphasizes that wonder goes beyond curiosity, and when performed correctly wonder transports the reader to a deep state of knowing what it is like to experience something.

Theme analysis. ***Existentials*****.** The themes for this analysis were in part generated through a process of reflecting on each anecdote regarding how it might related to the existentials, as described by Van Manen (2014), including body, social, space, and time. Each of these existentials was used to wonder about the deeper meaning of the experience. For example, how is the participant aware of their body or unconscious of its experience? How is the social interaction supportive/accepting or not supportive/rejecting? How is the space private/safe or public/unsafe? How is the period of time distinct from others? A major theme that recurs through many of the life stories, related to time, is change. How does a single moment change the course of the individual's life? How does perception of the experience gradually shift? How does someone not perceive change at all?"

References

Creswell, J. W. (2013). *Qualitative inquiry & research design: Choosing among five approaches.* Thousand Oaks, CA: SAGE Publications, Inc.

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52*(2), 250-260. doi:10.1037/0022-0167.52.2.250

Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of Counseling Psychology, 52*(2), 126-136. doi:10.1037/0022-0167.52.2.126

Wertz, F. J. (2005). Phenomenological research methods for counseling psychology. *Journal of Counseling Psychology*, *52*(2), 167-177. doi: 10.1037/0022-0167.52.2.167

Van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing.* Walnut Creek, CA: Left Coast Press, Inc.

Appendix C

Interview Guide

Interview 1: Estimated time 90 minutes

Informed Consent & Introduction

<u>Introduce myself</u>

I have worked with the alopecia areata registry, the national alopecia areata foundation, and clinical trials at the University of Minnesota. I learned a lot about alopecia areata. I have never had AA myself, but my work has made me very interested in how it affects people. I want to use my research opportunities as a graduate student to learn more in a systematic way about how alopecia areata affects people who have it.

<u>Informed consent</u>

Review consent form.

<u>Explain the process of the interview</u>

What I really want to know about you is how alopecia areata influenced the way you feel, think, or the things you do. As you talk about your experiences today and during the second interview I am going to ask you questions and direct you to describe very specifically and in many details the feelings you had during your experiences, the things you were thinking, and what you did in reaction to the experiences.

I also want to make sure I am understanding what you are saying, so I might repeat back what I think I heard and ask you to clarify if that is correct or if you think of it differently.

Establish Context of the Participant's Initial Experience through to Diagnosis

<u>1. A. Pinpointing the beginning of the experience</u>

Think back to what <u>you</u> consider to be the moment your experience with alopecia areata began. Tell me everything you can remember about that moment/day.

How would you describe yourself in that moment/day?

Example prompts:

- Feelings: *What were you feeling at that time? How did that feel? What other feelings do you think went with that experience? How did you know you were feeling XXX?*

- Thoughts: *What thoughts were going through your head? What were you thinking at that time? What other thoughts were going through you mind?*
- Behaviors: *What did you do after XXX?*
- Other: *What, if anything, about the experience surprised you?*
    - Questions that address Van Manen's 4 things – while thinking of the moment day:
        - Lived space: *Where are you? What is around you?*
        - Lived body: *What, if any, sensations do you notice in your body? How are you thinking about your body? What is your body doing? Are you moving or still? Sitting, standing, or lying down?*
        - Lived relationship: *Are you alone or with someone else? How do you feel having someone else there with you? How do you feel about being alone?*
        - Lived time: *In what order did you experience…? How did time feel?*

Note: If a participant uses wording that suggests an opinion rather than concrete details about their experience, I will gently request the participant, *"Describe an actual situation… starting beforehand and walking through the experience from its beginning through what happened afterward."* I will also use questions from the prompts listed above to further direct the participant to describe concrete details of their subjective experience.

Summarize:

Choose potentially salient feeling words, thoughts, or concepts the participant used in their descriptions. Present those words to the participant to determine what, if any, the participant considers essential to their lived experience.

E.g., *I heard you describe yourself as feeling confused in the moment your alopecia areata began. Tell me more about that.*

1. B. Details about the experience through to the diagnosis

Direct participant using prompts to describe additional events (e.g., When/if your alopecia worsened, When/if your alopecia improved).

Direct participant using prompts to describe the process of obtaining a medical diagnosis.

1. C. Demographics & Clinical Information

The content of these questions may have already been covered in the course of the interview. In that case, they will not be asked.

How would you describe your self-identified race or ethnicity? You may decline to *answer.*

Alopecia Areata History Questions

What is your current AA diagnosis? How was that made?

What treatments have you used?

Does anyone else in your family have alopecia areata?

Alopecia History

Age at onset of first episode: _________

Date of first episode of alopecia areata: ___________ / __________

Month Year

Number of alopecia areata episodes excluding initial episode: _________

History of alopecia totalis or alopecia totalis/universalis at any time: ☐ Yes ☐ No

If yes, duration: ______________

Alopecia Current Episode

Age at onset of current episode: _________

Approximate date of current episode of alopecia: ___________ / __________
Month Year

Perceived Contributing Factors

Perception of trigger for hair loss:

Initial episode: ____

Current episode: ____

Comments: ____

____

____

Interview 2: Estimated time 90 minutes

Interview 2 Part 1: Reconstruct the Details of the Participant's Experience

2. A. Defining what the experience is like now

Tell me about your experience with alopecia areata at the present time. Pick a specific day, perhaps one this week, and walk me everything you felt, thought, and did regarding your alopecia areata during that day. Let's start from the moment you woke up, and work our way to the moment you fell asleep.

How would you describe yourself today in regards to your alopecia areata?

Use prompts and summarizing statements to further define and clarify the experience of this particular day in the life.

- Questions that address Van Manen's 4 things – while thinking of the moment day:
  - Lived space: *Where are you? What is around you?*
  - Lived body: *What, if any, sensations do you notice in your body? How are you thinking about your body? What is your body doing? Are you moving or still? Sitting, standing, or lying down?*
  - Lived relationship: *Are you alone or with someone else? How do you feel having someone else there with you? How do you feel about being alone?*
  - Lived time: *In what order did you experience…? How did time feel?*

2. B. Further defining the contours of the present experience

If stated experience is different from the initial (interview 1), and has not already been covered under 2.A.

You stated you experienced XXX with your alopecia areata on the day you described. Describe another day where your experience of XXX was similar or different?

2. C. Defining other significant events in the experience of alopecia areata

Between the day you received your diagnosis and the recent day you described, what other moments or days do you feel like are memorable regarding your alopecia areata?

If additional experiences are brought forth, record a list of those experiences. Ask the participant to describe in detail their experience on that moment/day.

Tell me about your experience with alopecia areata on YYY (the new day the participant brought up, e.g., your wedding day, the first day you went in public without a wig).

If the participant brings up a NEW emotion, thought, or concept, explore additional details:

You defined experiencing XXX (emotion, thought, concept) with YYY (special day). How else have you experienced XXX (emotion, thought, concept)?

Use prompts and summarizing statements to further define and clarify the experiences related to the new moments/days.

2. D. Filling in details about the experience that have not been addressed

In the case that the participant has not already discussed the following and they are applicable.

1. When/if your alopecia worsened.
2. When/if your alopecia improved.
3. Undergoing treatments.
4. When/if you decided to stop treatment.
5. Your experience of alopecia during significant life events: high school, college, dating, marriage, having a family, etc.

Interview 2 Part 2: Reflections of the Meaning of the Experiences for the Participant

Ask the participant to reflect on the meaning of experiences.

Example questions:

Given what you have said about XXX before you got alopecia areata, and what you said about it now, how do you understand your experience of alopecia areata in your life? What sense does it make to you?

Given what we have talked about in these interviews, how do you see yourself experiencing alopecia areata in the future?

Appendix D

Individual Psychological Structures

At the ideographic stage of analysis there is minimal comparison across cases; each participants' data is analyzed as they presented it. The product of the ideographic analysis for each participant is what Wertz (2014) refers to as an "individual psychological structure;" a summary that integrates the researchers' reflections on the meanings of participants' individual experiences (e-book, p. 156). As with the results of the general analysis, anecdotes are used to present participants' descriptions. While anecdotes are not verbatim quotations, they are presented here as block quotes surrounded by the researchers' reflections, questions, and interpretations (See Methods and Appendix B for additional details and rationale). The individual analysis was completed by reflecting on each participant's set of anecdotes on two levels: (1) meaning of the whole life story and (2) meaning of the anecdote as a part of the story. The individual psychological structure follows Wertz's (2014) model. It is first presented as an evolving life story made up of anecdotes of reported lived experiences with AA over time. Additional structures are sometimes presented as (2) the participants' typical day, (3) their view of self, or (4) miscellaneous experiences.

Participant 1

The Life Story

Summary. Sienna's experience with AA was shaped by and experienced through supportive experiences with family and friends. She feels she developed an inner strength and confidence prior to developing AA. She was generally not fazed by her experiences with AA, including increasing hair loss, being teased, and getting a wig. She developed a desire to be "open" about her AA over time. She used a number of medical treatments, but eventually decided she has accepted AA and "enough is enough." She has "frustrating" and "cruel" encounters with strangers when not covering her AA. She wants to use her gifts to educate and provide support to others who may feel alone or have difficulty accepting their AA.

Detailed description. Sienna's description of her youth provides context for how she feels her early experiences with social support were developmentally significant in shaping her generally unfazed response to AA across her life. She explained that before the AA, she went through a process of developing confidence and a belief that she was a strong individual in the context of her family's support.

> I have always been a strong individual, I come from a large Italian family that always showed me love and support, more than I could ever ask for. And I was very active in school and softball and dancing and, so I grew up being very confident with myself.
>
> I started dancing jazz, tap, and ballet when I was two years old. I grew up with my older brother teaching me how to play baseball. We were always very active. My family was always at my dance recitals cheering me on. They were always at my softball games cheering me on. They would never miss a recital. They would never miss a game. My dad had a convenience store that he owned, but he would always make sure that he was at whatever event I had going on, because that was his priority. He showed me – my mom, my brothers, my grandparents – through their actions, they showed me their love and support by being there. By being by my side from the get-go, even before the alopecia.

In addition to developing a strong bond with her family in her youth, Sienna's description also suggests she developed a strong relationship with her body. She was active, busy, and had talents developed through support and guidance from family.

Sienna does not remember many details about when her AA started as a teenager, proposing it was a rather unremarkable experience.

> I was about 14, 15 years old. I just remember that it started as random thinning of my hair. I had a receding hairline. I remember my best friend's mom was a hairdresser and she had some Nioxin shampoo and conditioner that she suggested I use. So, I started using that to try and help with the thinning of the hair. And I remember going to the dermatologist and being diagnosed with alopecia. I do remember the first visit. I remember being in there, seeing the doctor. It was a male doctor. I remember him telling me that I had alopecia. And my mom was there. I didn't really understand it or comprehend it. I didn't really know what was going on, but I remember him telling my mom that he was going to prescribe me certain creams. And that's what I remember from the visit. I mean it was fine. I would apply it and put it on as instructed. I didn't really have any hair growth though.
>
> I just felt like it was something else that God put in my path and that I just needed to keep moving forward. It didn’t really bother me, and I just saw it as something else, another challenge in life. But I didn’t think I was ugly or that I wasn’t good enough, because my family always told me, “You’re the most beautiful young woman.” With everything that I was doing - I was so active, I was so busy that it didn’t really faze me.
>
> The love they showed me by being there just meant so much. It made me feel like the young woman I was becoming. I knew that it was okay and it wasn’t my fault.

Sienna re-emphasized the importance of her social support and her strong body, and introduced her faith as helpful in orienting her experience of AA as a challenge – something outside of her and that could be overcome with strength of character. Sienna implied her activity and busyness somehow protected her. She perhaps alluded to previous difficulties by specifying the AA was something *else* to overcome.

Sienna continued to describe the people close to her as allies in her remembered experiences. In one event, her mom noticed a bald spot while helping Sienna prepare for a significant event in which her appearance featured prominently.

> I remember I was getting ready for the junior prom. I had thick, curly, long dark hair, and I always thought that my hair was my best physical characteristic. I was parting my hair on the side like J. Lo did, she was popular then, and I wanted it parted on the side in a bun. I had my beautiful dress and I had my makeup on. My mom was doing my hair, and she saw the bald spot. It was like an inch from my forehead. She just told me about it, and she said, "Oh that’s fine. We’ll just fill it in with some dark brown eyeliner." For me it was like if someone broke their arm or they fell of their bike and got a scratch or a cut. It was just like, "Okay you got that." And you just keep moving forward. It was kind of like that for me. It wasn’t like I was like, "Oh my gosh! I am so ugly. What am I going to do?" It wasn’t like that. It was just like, "Okay. There is a spot. We’re going to fix it right now by putting eyeliner on it.” And that’s what we did, and then I went on and had a great time at the junior prom. And it wasn’t a big deal. It didn’t really faze me. I had a prom date that adored me. It was my boyfriend; he knew about it. He knew about the alopecia. But he saw me for who I was inside.
>
> I was just 16 or 17 years old. But I’ve always been really strong and mature, and not really focused on what you had to offer to the world based on your outer appearance. I was really strong spiritually, and I knew that what was important was what was in my heart.
>
> I think it was because I had the support of family and friends around me, supporting me in every area in my life, especially emotionally. I couldn’t have done it without them. If I didn’t have them supporting me, I don’t know how I would have reacted. I’m grateful that I have a family that loves me, and supports me no matter what.

Comparing her bald spot to a wound suggests Sienna viewed AA as something that happened to her body; it did not take on additional meaning as something to be ashamed of or impact her view of herself. In the beginning, her AA was only a physical experience. Soon she came to experience it as a social phenomenon.

Sienna described other memories where increased hair loss became a source of rejection and derision from her peers. This started when her AA was "exposed" and "public."

> I went to an all girl’s catholic school, and my boyfriend went the co-ed

> catholic school. The schools were a mile apart so we rode the bus together. I remember my bald spot was getting worse, and it was exposed when I was in public. We were on the bus once and the kids that went to his school, they broke CD-ROMs and were throwing them at me. And they were cursing at me and telling me, "What the F is wrong with you? You look like an alien. You are disgusting." And they were saying very hurtful, cruel things. I have never been the fighting type. I'm such a lover. It was very shocking to see someone behave like that, especially because I wasn't trying to do anything mean to them. They were just mocking me for something that I didn't choose; I didn't choose to have alopecia. I felt bad for them, and thought like, "Wow. What kind of hearts do these people have? They must be hurting in their life somehow that they could feel that it's okay to bring someone else down." I felt bad for them because I knew that they were not right in their heart that they wanted to bring someone else down.
>
> My boyfriend stood up for me to them. After that we decided that we were going to drive together to school and not take the bus anymore. He stood by my side and showed me that it was okay. And that's an example of my boyfriend really acting out support and care. I was happy that he was understanding, that he was supportive and he was going to try and do something that made my day a little easier. And maybe he was going out of his way, but he was going to stand by my side.

Sienna again omitted mention of shame or embarrassment about her appearance. While experiencing rejection from these students, Sienna was not concerned with it. She focused instead on the acceptance from her boyfriend. But the experience did change something for Sienna; the bus was no longer a safe space for her. Sienna and her boyfriend would go out of their way to avoid it.

While in college, Sienna's hair loss continued to spread until it covered the crown of her head. Rather than leaving the hair loss "exposed," as she had done when her AA increased in high school, she now covered the spots.

> Once I started my first year of undergrad, my hair was so long it was down to my butt. And it was very curly and dark. In that first year of college, it started balding right on the crown of my head. But I was able to conceal the bald spot by pinning up my hair. I did that for a while. I worked as an

> athletic trainer at the college where I went, and I remember wearing like pink or red bandanas to work in the gym to hide the spots.
>
> I remember my junior year of college and the bald spots had gotten so bad that it was the whole crown of my head, all over, and behind my ears. It affected me to lose more hair, but I didn't feel crushed. It didn't really bother me. I was very active and always busy, and so I didn't really think too much into it. I just like went with the flow. I rolled with the punches.

Sienna said nothing about how the routine of pinning or covering her hair was experienced, perhaps alluding to it being a passed-through-experience, something that did not pull her out of the unconscious experiencing in which we live most of our lives. She insisted the hair loss was not distressing. But to roll with the punches assumes there is adaptation to something adverse; a need to shift so the punches of life land with less force.

As the hair loss progressed and Sienna was preparing to study abroad, she explored wigs as a new option for managing her AA.

> My mom suggested that I buy a wig, which we did together. We got a wig that was similar to my hair; it was very curly, long, dark brown hair. Being a girl, it was just like buying another accessory, like another pair of shoes. We went to the wig shop and I tried ones that I liked. I picked out a really nice wig. And, again, I just rolled with the punches and made the best of it. I stayed positive. And that was when I started wearing the wigs and the scarves.

Notably, Sienna's first wig matched her hair color, length, and texture. It would thus maintain her typical appearance.

Sienna described some discomfort in wearing the wig. The wig was irritating: "It was uncomfortable at times and hot. And it would itch." These physical effects could not be mitigated. Psychological discomfort, however, could possibly be managed with ingenuity and resourcefulness.

> Shortly after buying the wig, I was studying abroad in Italy. I remember wearing the wig when I was in Italy, here and there. I remember feeling self-conscious that other people knew I was wearing a wig. I wanted it to be like so natural that people wouldn't know. I remember that I was very concerned that other people knew that it was a wig. I would try and style the hair a certain way that it would look the most natural. That first wig that I had, it wasn't advanced the way the wigs are these days. They didn't have lace-front wigs, so it didn't have a natural hairline. What I did was I would create a swoop bang. I would pull probably a handful of hair from the front, and put that hair strand behind my ear and tuck it under the wig. I would do the same thing on the other side. I tried to make it look as natural as possible. And I actually did a good job with it. And a lot of people didn't know it was a wig. And girls would come up to me and say, "Oh, I love your hair." They think it's my hair.
>
> As a woman, it's an accessory to me. It's not my hair. It's just like when you wear anything with your outfit, or when you have your makeup on. If you put on fake eyelashes, you don't want someone to know you are wearing fake eyelashes. I take pride in getting dressed and it's a way to express myself creatively. I'm kind of a perfectionist, so I don't like anything to be out of order. I just always wanted to be as presentable as possible. I guess I could compare it to a woman that has a boob job. I don't have a boob job, but I know some women that have them. They don't want enormous breasts. They want a natural-looking breast. They don't want people to know they had a boob job. But they want to have nice, perky breasts. It's like the same thing with the wig. I want it to look natural. I don't want to draw a lot of attention to myself. But just like any woman, I want to be beautiful. I want to look my best. But I don't want to look like I'm trying so hard.

Referring to the wig as an accessory distinguished it as separate from her body or an embellishment. Sienna normalized the experience of not wanting to "draw a lot of attention" to herself, suggesting that it was perhaps not a fear of rejection or her AA being exposed, but a typical desire any woman would have to appear effortlessly "presentable."

Sienna shared another source of discomfort with the wig was concern about other women comparing themselves to her.

> It happened several times where girls would come up to me and be like, "Oh my gosh! I love your hair! How did you do that? I wish my hair was like yours." And like immediately I would say, "Oh my gosh! This is a wig! Are you kidding?" I didn't want her to think she wasn't good enough when here I'm wearing a wig. I always felt guilty if I would say, "Oh yeah, you like my hair?" I always would just tell people that I was wearing a wig, because I didn't want them to get down on themselves looking at my hair. Then I would go right into, "I have alopecia" and I would tell them what alopecia is.

Perhaps Sienna felt uncomfortable not disclosing her hair was a wig because it would not be authentic; by telling strangers the source of her AA she rejected duplicity.

Sienna described a memorable event while she was studying abroad during college, in which she experienced seeing a confident woman with AA exposed.

> When I was it Italy I went to the grocery store right near my apartment in Rome. One of the cashiers, she was a probably a 50-year old Italian woman. She was very beautiful and confident. I don't know if she had alopecia, but she definitely had some type of hair loss. She literally had like 20 strands of hair, and wore them up in a scrunchie. She was so confident. It made me feel happy to see her in public like that, like it didn't even faze her. That always sticks in my mind that I saw that woman.

Seeing someone willingly exposed but still remaining strong and confident was inspiring. It may have confirmed Sienna's beliefs that what makes a woman beautiful is her confidence, not her hair or the lack thereof.

Sienna also described some of her experiences with intimate relationships after she started wearing wigs, revealing that exposing her AA did not change intimate partners' views of her.

> I remember once I came back from Italy I bought a bunch of different wigs. And they were different lengths, different colors, different styles. I had a boyfriend at that time and he told me, because I had so many different looks with the hair, that he felt like he was cheating on me with me. And I always thought that was funny. And because most of the bald

> spots were on the crown of my head, like a perfectly circular bald spot, he told me that was my halo because I was an angel. And I thought that was really sweet. He was fine with it.

The comments from the boyfriend turned the various ways he experienced Sienna's AA– having different wigs, the location and shape of her hair loss – into positives. This was a way of emphasizing that her AA did not diminish her in his eyes.

Sienna described that her experiences dating over the years have not been problematic; men tend to admire her for her confidence and see beyond the AA.

> I found over the years the different men that I have dated are totally fine with it. They are attracted to me because I'm so confident and comfortable with who I'm that they don't really see the alopecia. I have not had problems dating because of it. They see who I'm as a person and how strong I'm, and they are pulled to that.

To demonstrate what this experience was like for Sienna, she provided a specific example of a date in which her openness about her AA was perceived as attractive. This example also demonstrates Sienna's approach to disclosing about AA to potential intimate partners.

> I can't keep a secret. I want to tell people straight up, right out about the alopecia. Usually when I first meet someone I tell them. I remember meeting one boyfriend at a coffee shop. He was sitting at a table, and I sat at the table where he was sitting. We just started talking. I had a scarf on at that point. I'm just so moved when I meet someone. I'm really honest. Something in me just wants to tell people. I remember telling him about alopecia, and I actually pulled off the scarf and showed him the alopecia. He later told me that he was shocked that I was so comfortable to tell him. And he thought to himself like, "Wow. Maybe she thinks that I wouldn't be attracted or that she is pushing me away, but I'm actually attracted because she is so honest and so comfortable."
>
> Then I pulled out my phone and showed pictures of me with a wig on. It was like the three people I feel I'm that are living this life in one body. I met him with the scarf on, I felt moved to remove the scarf to show him the second person, and I wanted to show him how hot I look with the wig

> on. Then I showed him the picture of the wig.

Sienna felt “something in me” on her date that pushed her to disclose – an irresistible impulse. Their conversation became intimate quite quickly; she revealed a part of her private world to this individual in their first meeting. After explaining her AA and baring her scalp, Sienna felt a desire to show a photograph of herself in a wig. She revealed to her date all three ways she presents herself to the world – scarf, no scarf, and wig (this is described in more detail later).

Sienna also talked about experiences with friends who knew about the AA and similarly responded to her by confirming their appreciation for her and her appearance.

> And a lot of my friends that I went to high school with, or friends from college were like shocked how good I was handling it. And they were like, "I could never do what you are doing. I would literally die." And I just made the best of it, and stayed positive. I didn’t think so much of it.
>
> I remember my two best friends would always say, "You wear your wig so well. You are so confident with the wig on, or without the wig on. We really support you. We think you are so beautiful and amazing. We never could do what you do. You pull it off so well." And a lot of times my friends would say, "Oh, let me try your wig on." Or, "Can you put one on me?" We made it like a fun thing. It was like dress-up.

Sienna experienced her friends’ statements as supportive. Perhaps she felt the comments were affirming her strength, and providing feedback that she was successfully living her life in accordance with her value that what is inside is more important to her than physical characteristics.

Sienna explained that over time she started to feel a greater openness and desire to share about her AA.

> In high school, the alopecia wasn’t really bad. But my family, my friends knew about it. In college, it started getting bad, and pretty much the people

> I was close with knew about it. I would say when I went to law school, I was more open with it. I guess as I matured I wanted people to know. It has happened over the years.

The circle of individuals who had knowledge about Sienna's AA grew.

As Sienna became more open about her AA, a new reaction emerged when she was confronted by negative reactions in public: annoyance.

> I remember one time, probably 5 years ago, I was at a park with my dad and brother. We were walking on the sidewalk. There were some young kids, and the kids started mocking me. I didn't have a scarf on or anything covering my head, so they saw my balding. They were cursing me and saying mean things. And it just took me back to the bus ride. Again, it was just like, "Wow! What is wrong with your heart? What is happening in your life that you want to bring someone else down?" I wasn't really hurt, but it gets annoying. It just gets frustrating. It's never ending. I have to prepare myself mentally when I go out in public with no scarf.
>
> My brother got very protective and wanted to beat up the kids. And I told him, "Just ignore them. It's okay." But he was really mad. The fact that he got all riled up about it showed me that he cared. He was willing to fight someone that was talking nasty about his sister. That was his way of being protective and supportive.

Sienna would perhaps like to be able to go about her day without being aware of her AA, but the frequent reactions of others force her to be conscious of its presence. Sienna shared this encounter as an example of a situation in which her family member showed support through the sheer intensity of his emotional response.

In the present day, Sienna explained the source of her annoyance and frustration was that she has accepted her hair loss, but the world around her has not.

> I have accepted my hair loss, and I know that I'm beautiful the way that I'm. Most days I feel like wearing my scarf. But when I'm at the beach or when I'm with my family and friends, I'll usually remove the scarf. Sometimes that may be in public places. At this point in my life, I have accepted it and I'm fine with the alopecia. But I know that it's the world around me that has not accepted it, usually people that don't know me. If

> I’m at the beach, I’m in a peaceful setting and I just want to relax my mind. People will be around me, constantly staring. It gets frustrating because I feel like I have accepted it, why can't they accept it? It’s annoying because I have accepted it, and I want them to accept it. Sometimes I just want to be left alone and have my time to have some serenity. Especially if someone is trying to be mean, or bully me, or laugh at me, or say mean things; then it’s really frustrating. But at the same time, I want to educate them.

Sienna’s opinion of herself was not decreased by the negative comments, but she felt frustrated by their pervasive disturbance. She felt of two minds about her experiences with people in public regarding her alopecia: both annoyed that people have not accepted her AA, and a desire to educate them.

The nature in which strangers approach Sienna and interact with her about her alopecia makes a difference for her emotional response. Sienna described a specific example in which she received negative attention for going in public without a scarf or wig.

> If it’s a child or it’s an adult who is approaching me and saying, "Wow. I’m really curious, what do you have happening?" That’s not so bad. If it’s someone watching from a distance, and they are being mean, then it’s frustrating.
>
> One time I was by myself at the beach, and I didn’t have a scarf or anything on my head. There was bridal party that just had their wedding, and they were taking pictures on the beach. A couple groomsmen were looking my way. They were shouting and they were saying, "Oh my gosh." They were cursing and saying nasty things about me and, "What the F is wrong with her? Do you see that over there? You should get that thing in the picture." And the thing he was referring to was me. I thought it was just very rude, disappointing, and frustrating. Here an adult man who is trying to bully me. It was very sad in the moment. I just ignored them. I didn’t say anything. I figured this wasn’t someone that was trying to learn about what was happening with me, or this is not someone that’s concerned with another human being. They are concerned with trying to be a comedian, and trying to impress others by bringing another person down. I figured it wasn’t even appropriate for me to say anything because

> it wouldn’t have made much of a difference. If that’s the mindset that they have, which is very evil, then I wasn’t even going to waste my words on them.

Sienna was labelled by the strangers as a “thing” for being in public baldheaded. She, again, did not internalize others’ comments to mean anything about who she is as a person.

Throughout Sienna’s experiences with AA, she visited a dermatologist and underwent treatments in attempts to generate hair regrowth. Some experiences at the dermatologist stand out for her. For instance, she described feeling mixed emotions in an interaction with a medical student.

> I remember laying face-down in the dermatologist's office. They had a medical student, and asked if it was okay if they could take pictures of my scalp. I said "Yes. Of course.” I always want to help any research, or help another person learn. But at the same time, I felt like a rat or a mouse in some laboratory.

She felt a desire to contribute to the AA community, or be a resource to future medical providers. Yet, the process of being photographed by the medical student felt dehumanizing and indifferent.

Sienna spoke more specifically to the experience of undergoing cortisone shots, estimating that she had them approximately 20 times over two years. This was despite feeling serious anguish. She explained:

> Over the years there was a lot of different creams, and oils, and vitamins, natural remedies, and cortisone shots. Having cortisone shots was the worst pain of my life. My gosh, that was horrible! I remember my grandpa came with me a couple times for the cortisone shots, and like he felt so bad for me.
>
> I remember when they would do the shots on my forehead near my temple; that was the worst. I really had to be strong in the moment. I could

> feel the medicine go in my head, and it would burn. It wasn’t a happy experience. I would just lay there and take it like a champ, and just work through the pain. I wouldn’t moan or groan. I tried to be strong. I let the doctors do what they needed to do. I tried not to flinch or mess anything up. But I saw it as just like going to a regular doctor. If you have to get a certain procedure done, and they prescribe you a medicine. I just thought of it like that, just another doctor’s appointment.
>
> I did the cortisone shots for a few years, maybe like two years, on and off. It was more than a couple times a year; maybe it was like 10 times a year. And my alopecia’s been steady for the past 10 years, where 90% is gone. I've done several treatments and nothing is really happening. Now I realize that the cortisone shots left dents in my head. It’s not a good thing.

Even her relatives who came along to show support expressed distress at seeing her go through the process. Sienna thought to herself about the importance of the process, like any other appointment with a doctor. Again, the AA was not a part of her – but something that happens to her body, like any other illness. She pushed through the pain of the treatment, because that was her expectation for medical care.

There were also an unexpected negative consequence to treatments. After discontinuing the cortisone shots, Sienna eventually participated in a clinical trial and had an adverse response.

> They were testing an FDA-approved drug used to lower cholesterol. For some reason, it was going to help people with alopecia grow their hair back. I did this study for 16 weeks. My body didn’t react positively to it.

The research study led to an experience in which Sienna’s attitude about and approach to managing her AA shifted.

When Sienna started a new treatment, her frustrations with the discomfort and tedium of treatments came to a head. This was a pivotal moment for her, which led to a new way of living her life with AA.

After the research study was over, the doctor offered to treat me with a cream. I used it 6 days a week for 6 months or 10 months, and Wednesday was my only night off. So nearly every night I had to put cream on my head, and wrap my head with Saran Wrap. And my brother gave me the nickname “alien,” because I looked like an alien with my whole head wrapped with plastic wrap. Then I would go to sleep. I would be sweating like crazy, because I had the plastic on my head. I remember the feeling of removing that plastic wrap when I woke up. It had my sweat and the cream inside, and it was like the worst feeling. I would just go right in the shower and wash my head. It wasn’t a fun experience. The treatment wasn’t working. That’s when I just felt so sick of it. After that I was just not motivated to try the next treatment. I decided that the most important part of this process and a real treatment for me is emotional. It has to be emotional because physically nothing is working.

For me, and I think for the majority of people, it’s really important to have a solid support system. I really focus on the alopecia support group. And I just relied on the support of my family and my friends. That has been what has gotten me through the day to day.

Nothing has worked physically. Emotionally, God's treatment has worked for me. Where I know that, that he loves me, that he made me the way he wanted to and that was a perfect way. And I didn’t doubt his plan at all, and I don’t regret having alopecia. And I know that it has made me a stronger woman, and that it has introduced me to so many people that I would have never met. For example, in our support group, or just people that I meet randomly when I’m talking about my alopecia. So, just knowing that I have my God, and having a personal relationship with him has helped me enormously. I couldn’t have done it without him.

Right now, I’m not doing any treatments. I’m just so frustrated with all the treatments. I just accepted the alopecia, I’m happy with who I’m. I do get frustrated at times when I’m in public where people are staring and whispering. But in regards to the treatments, I really don’t want to do any treatment anymore. I’m just over it.

Because with alopecia even if I do treatment, like, in my eyes it’s like, if I do treatment and my hair grows back like, am I going to do this for the rest of my life? Like for me to put cream on my head or whatever it is every night, every day, if I had my hair back, like, I would rather just not have hair. Because it’s a lot to like do it every single night or whatever it is, and then I can't take a shower or I have to shower or I have to wait an hour and, it’s just like time consuming and it gets annoying. I don’t know if I sound like a brat or I’m not trying to be ungrateful, but it gets so

> annoying. I have heard people who are on different diets where they go vegan or gluten free or no dairy no sugar, and their hair grows back. For me, like, I come from an Italian family, and we are obsessed with food. I love food. I love eating. I love cooking. I love being in a kitchen with my family and cooking. For me, it’s not worth it. I would rather eat and enjoy my life than deprive myself of gluten or whatever it is just so I could have hair. But a lot of times with alopecia, even if someone's hair grows back, you never know, you could lose it again. For me, I would rather live my life and do the things that I like and eat the things that I like, rather than deprive myself. I don’t know if that’s bratty of me or what? It’s just like, enough is enough. I have done so many treatments, nothing is working, and I would rather just live my way.
>
> I have a feeling in my heart like I should do the treatment to give hope to the children in the support group; I don’t want them to think that I’m giving up. But not doing treatment, I don’t believe that I’m giving up. That’s my choice. I don’t think that’s wrong.

After months and years of painful or uncomfortable bodily impacts of medical treatments, the time-consuming and uncomfortable routine of this final treatment led Sienna to say “enough is enough.” Sienna reprioritized what she saw as living her life unencumbered by any medical treatment or dietary restrictions. As she transitioned to no longer pursuing medical treatments, she emphasized using social and spiritual support as her new remedy for AA. Sienna also mentioned a new potential theme: autonomy. While prior decisions about medical treatments may have tended toward taking recommendations from a doctor or doing whatever she could; now she was making a personal decision based upon her experiences.

Sienna’s shift from medical treatments to acceptance may be difficult for some in her life to understand. She described a recent specific event.

> Right now my dad is pressuring me to try new treatments. He heard something about vinegar that’s supposed to help hair growth. He is forcing me and pressuring me to put vinegar on my head every day. I live with my father. The other day I was getting ready to go in the shower, and he is

> chasing me around with a bottle of vinegar. He insisted on putting it on my head before I went in the shower. I just let him do that. I told him it's not going to make a difference to do it once. And he is like, "Oh, why don't you do it every day?" I appreciate his support, and I appreciate that he wants me to have hair. But for me I just don't need hair at this point. I don't even remember what it was like to have hair. I'm just comfortable with where I am at right now.

Sienna's father continued to try to support her, but the nature of the support she needs has changed. While her father focused on new treatments, Sienna herself is no longer interested in these efforts.

Sienna talked about how she started the support group out of curiosity, and it has developed into an additional source of support for her as well as others.

> When I did the research study, that's actually when I created the support group. They didn't have a chapter, and I was like, "Wow, I wonder if there is other people with alopecia like me? I would love to meet them and work through it together." That's when I created the support group. I have been the support group leader for over three years now.
>
> I see the support group as a team or as a family. And when you have a team, people are playing certain roles but they're all there for a common purpose. And our common purpose is to have a comfortable, safe, secure, uplifting, positive environment for people with alopecia. And to educate others about alopecia.
>
> Over the three years that I've been the support group leader for the group, the group has grown and grown and blossomed. And we all have created life-long relationships amongst each other. And there's always a new member calling me on the phone looking for support, asking about the group, asking when the next meeting or fundraiser is. And, it's something that I'm so grateful for in having the group, because it's such a beautiful, never ending gift that someone who doesn't have alopecia and who's not part of the group, they can't really relate to. Unless you're relating to like another group that you're in. But the closest thing I can relate it to is like a family, because a family is constantly growing - people are getting married, people are having children. It's something very special, where every day there's new people joining the group. Every day, or every meeting is a new event or a new opportunity for all of us to get closer and to talk about our recent experiences with alopecia and to update each

other.

The shared space with others brings Sienna a new sense of community and fellowship with others who have AA.

Sienna also described her own family's role in the support group. She lists the various ways they are involved: "They help me plan, shop, and set up for the meetings." She also described the ways her family members show support for others in the group, in a way that even Sienna feels she could not do herself.

> My dad is my go-to for parents that call me in regards to their children that have alopecia. I can speak to someone that has alopecia and really relate to them. With a parent of a child that has alopecia, I can talk with them but I really can't connect in a way that a parent with a child with alopecia can. Any time I have a parent that calls me, I immediately tell them about my father. I ask them if it's okay if I give my father their phone number. And my dad usually calls them and will be on the phone with them for an hour or so. And he can connect at a whole other level. They are so grateful. They love talking to him. They laugh and cry. He is very supportive in that sense. He takes time out of his busy schedule to talk to these parents. And he loves it.
>
> I just had an alopecia support group meeting, and my dad decided that he was going to shave his head. This was probably the 15th meeting that we have had, but for some reason my dad was so moved that he decided he was going to shave his head. He told me that if I have to keep going to these meetings bald, then he is going to go bald too. He was so excited about it. He had my brother record him shaving his head. My dad was very proud about it. He was so excited the next day to show up at the support group with his shaved head. That was another action where he was showing his love and his support. I was very grateful. I was also kind of shocked, because he has really nice hair and he loves his hair. But I felt happy, I felt grateful. It was nice to see him the next day at the meeting, and he was walking around and smiling. He was telling everyone how he shaved his head for me. There was a sense of pride he felt just by me not having hair. It was moving.

Sienna's father joined her in exposing his baldhead to the AA community; he stood in solidarity and unity with her.

Sienna turned her own confidence and strength, developed under the support of her family and friends, to now want to bring support to others with AA and educate the world about it.

> A lot of times if I see someone in public that I think has alopecia, I’ll approach them and say, "Hi I’m Sienna." Then maybe they will say who they are. I’ll say, "I have alopecia. Do you know what that is?" And then if they have alopecia then they will start telling me about their alopecia. And if they say, "Oh no, I don’t know what that is." Then I’ll say, “It’s a hair loss disease that I have.” Maybe I’ll say, "I thought you had it." Or I’ll just say, "Oh, never mind," because sometimes people get a little weird with that. I feel I’m constantly obsessed with sharing about my alopecia or learning about someone else's alopecia. I want to invite them to our support group. I don’t want them to feel like they are alone.
>
> I have done this a lot where I’ll be in a grocery store or in a mall. If a woman comes up to me and says, "Oh, I love how you wrap your scarf! Did you do it yourself?" I’ll be like, "Yeah, I’ll show you how to wrap it right now." I literally pull off the scarf and my whole baldhead is exposed to this woman and whomever is around us. I don’t get fazed whoever is there. I just show them how to wrap the scarf. Then I’ll tell them about the alopecia while I’m there. I’m like an alopecia sergeant. I feel like I’m supposed to do this every day. I’m supposed to share it.

Sienna remarked that she does not feel fazed by exposing her baldhead to strangers. Rather, she feels a sense of purpose – a feeling that this is what she is meant to do with her life. As an “alopecia sergeant,” she is an officer for AA. She diligently recruits and educates, responding to the command of her calling.

Sienna reflected on how she experienced AA across her experiences, and shared how she feels the AA makes sense in the context of her life.

> For me it makes perfect sense. I really wouldn’t take it any other way. This is my life, this is the amount of hair that I have on my head. I’m exactly the way I should be. It has given me a purpose. It has allowed me to connect with others. It has allowed me to be confident and comfortable with who I am. And it has shown me that it doesn’t matter what is on the outside, what is most important is the heart that you have, the love, the

> care that you share and give to others. And it has really humbled me, and given me a life-long purpose. I believe that I was chosen by God to have alopecia. And that it's my duty and my responsibility to be there for people with alopecia - as I try to with the support group - and also to educate the community about alopecia. Because awareness equals acceptance, I believe.

She deeply and spiritually feels moved to be involved in the AA community, and feels she is living up to that purpose in her role with the support group.

While Sienna has been unfazed by her AA, some members of her family have had different reactions.

> My dad is very emotional about my alopecia, even though I have had it for over 17 years now. I never really cry about having alopecia. But if my dad was in front of me right now, if he looks at my hair, he starts making this face. It's actually a joke between my brother and I, because a lot of times like the three of us will be together. We can see when my dad is about to start crying. He makes this face and he shakes his head. He has like this frown on his head. And we are like, "Dad, stop!" And we'll just start laughing.
>
> My dad always has this saying. He will say, "Oh, my gosh. It hurts me. It hurts me to look at you like that." He can't help himself, he will just start crying. I want my dad to be the parent representative for our support group. He will talk to parents on the side, but he has a hard time speaking in front of the whole group because he will just start crying. Whenever he sees girls in public - you know how girls put their hands through their hair, especially like the center of their forehead, and they flip their hair around? My dad will come home and he will tell me how, "Oh I saw these girls flipping their hair today." And he is like, "I wanted to start crying." Or, "I wanted to pull their hair out." He gets angry when he sees girls playing with their hair. And I'm like, "Oh, my gosh, dad, stop!" And then he is like, "Oh, why can't you have hair." And I'm like, "It's okay. Like, really." Like he gets very emotional about it. My dad just wants the best for me, and he thinks that I'm lacking something in life without having hair. I have accepted the alopecia, but he can never accept it. He accepts me with the alopecia. He tells me I'm beautiful, and I know that he believes in his heart that I'm beautiful. But when I say he can't accept the alopecia, it's like he doesn't like the idea of it. Like he feels like I'm not whole.

> I don’t have children yet, but I can understand where he is coming from, where he wants the best for his children. It really shows me that he loves and cares for me. I’m grateful that I have a father that cares that much.

The rawness of the emotional experience of Sienna’s AA is still fresh for her father. Acceptance may take on a new meaning here: Sienna can feel his acceptance of who she is with AA, and understand his inability to accept her AA. She understands his persistence as another way her father shows support.

Sienna expected she will continue to be involved with advocacy and the AA support group in her future. She talked doing whatever she can to help find a cure, and using her expertise as a lawyer to help the world with AA if needed.

> One day at a time, continuing to get better every day in my personal life, in the life with the alopecia group, trying to do work as a person with alopecia. If there's any way I could help to find a cure or anything I'm open and I'm willing and I'm ready to help the world with alopecia. So that's one life-long goal that I have is to continue to be active in the alopecia community, and continue to embrace whatever life brings me. And have a family, and have children. And be the best person that I can be in all areas of my life.
>
> I really believe that my alopecia was caused by an environmental issue. I don’t know if I discussed this with you, but I think that it was caused by an environmental issue because my parents used to live right near an air force base in Las Vegas, NV in the 1980s. And, the military and government was doing a lot of testing there at that site. I believe that my parents ingested something that was in their bodies when my mom became pregnant. I was diagnosed with alopecia later in my life. Most of the children in that same community they lived in, their children have alopecia or thyroid cancer, so I really believe there is an environmental connection with alopecia. I don’t know what I could do on the legal end, but if there is anything I could do to try and help the future generations to make sure that this doesn’t happen again, to maybe see what went wrong. What went wrong at that air force base? What caused alopecia for me and other individuals in the community? And see what I can do to make sure it doesn’t happen for future generations.

The Typical Day

Summary. As Sienna described her current life, AA is a major component of her daily experiences. While there are some negatives to the experience – stares and comments – much of the experiences with AA involve the support group. She appreciates the time she spends leading the support group, as it gives her life a sense of meaning.

Detailed description. Sienna described her routine on her typical morning begins with processes she expects anyone might experience – she wakes up, takes a shower, and selects her outfit. These experiences have additional aspects for her, however, because of the AA.

> A normal day for a woman living with alopecia for over 17 years now. I wake up, like anyone else, do the normal daily routine. I take a shower. I have been recommended by doctors that I should not wash my hair as often, so when I do wash my hair my arms and my forearms get a workout because the muscles are not used to normal hair washing. My arms, forearms, and hands will feel sore the day I wash my hair.
>
> I always wear a scarf daily. I love wearing scarves; it's so my thing. When I pick out my clothes, I always make sure that my scarf matches my dress, my shoes, and my jewelry. The scarf is just another accessory that I use, and it's a big deal for me. The way I wrap the scarf is different every day; sometimes I'll tie it on the right side, or in the back, or in the front of my head. Sometimes I'll put a headband on with the scarf. The scarf is just another way that I accessorize my outfit and make sure that I look nice.

While most people might not notice many aspects of their daily shower, Sienna's experience in the shower is brought to her awareness through soreness in her hands and forearms if she washes her hair. Her morning routine helps her carry out her desire to be "presentable," as she explained was important in her life story.

Sienna described her AA is brought to her attention on a typical day while doing "normal things," like going to work and spending time with family. For instance, she is consistently reminded of her AA whenever she leaves the office at work because of the attention she gets from strangers.

> Throughout the day, like when I get coffee or have lunch, I'll find people looking in my direction. They might stare or whisper. I'll just smile at them, wave, and say "hello." Maybe they will look away quickly once they see that I'm looking. Some people will think that I have cancer, and will come up to me and say, "Oh, how is your treatment going?" I tell them that I have alopecia and I use that as an opportunity to educate them about it, if they don't know what it is. It doesn't hurt my feelings, but it does get annoying when people will constantly stare or whisper.
>
> Then I do normal things just like any 31-year old woman would do. I'll go out with friends, I'll have dinner, go to different events. When I'm at the beach or with my family and friends, I'll usually remove the scarf. Sometimes that may be in public places. When I get the attention of people that don't know me, if I'm not wearing a scarf, they will constantly be staring.

These experiences bother Sienna and consistently remind her of her AA, but they do not devastate her or change the way she interacts with the world. They are reminders that the world does not understand her AA.

Sienna shared that her involvement as leader of the AA support group is also a major component of her day. She described two specific interactions with support group members this week.

> A lot of my day is spent on the phone with people who have alopecia. I also get phone calls from numbers that I don't recognize, who are usually people asking for information about our group and how they can get support. Usually it turns into a few hours of my day where I am on the phone with these people, which I'm more than happy to do. And I try and give them support and give them direction and tell them about my experience with alopecia and what works for me on daily basis to help me be positive and keep going in my life.
>
> I met one of the support group members at Starbucks because we are planning our alopecia fundraiser for alopecia awareness month. This member is fairly new to the group, as he is only been to one session. It's such a breath of fresh air to see his spirit because he is probably around 40 years old and he had never met anyone else with alopecia. He said that he

> has been alone in his life regarding alopecia. He has not been depressed about it, but he has not been active in the alopecia community. He is so energetic, and wants to help in any way possible. It’s really nice when you have a new support group member coming on, and it reminds me of why I’m doing this. It reminds me that I’m helping someone. It shows me the meaning of life, which is to help others. And through helping others, I’m lifting my own spirits.
>
> I got a phone call on the day this week from a support group member – a mother who has an 8-year-old daughter with alopecia. The daughter just started school. The mother called me hysterical, telling me that three girls were tormenting her daughter. They were telling her, "You are wearing a wig. What is wrong with you? You are different." The bullies went to the extent of pulling the wig off the girl's head. And it was very emotional for the child and the parents. We planned for me to give a presentation on alopecia to the whole school, and I’m very excited to do it.

Sienna stated that she is “more than happy” to provide support and spend time on the phone, fulfilling her self-described mission of providing support to others with AA.

Current View of Self

Summary. Living with AA alternatively exposed or covered in public spaces naturally draws the attention of others in different ways. The repeated exposure to these different ways of interacting with the world has created in Sienna a feeling of having a “tri-life.”

Detailed description. Sienna described her view of herself as she is in the present is very positive.

> I see myself as exactly as I should be, exactly where God wants me to be. I see myself as beautiful, strong, confident, intelligent, a go-getter, a goal-achiever, someone with a very big heart. Someone that loves to provide service to others. I see myself as a regular woman who is doing what she should be doing in life.

Sienna views herself positively from multiple lenses. This view of herself comes primarily from an internal source at this time in her life – these are thoughts she has, rather than messages she receives about herself.

Sienna also described she has a view of herself that relates to how the external world responds to her. She calls this her “three-person life.”

> I’ve felt like this for many, many years. I feel like I’m living a triple life. I actually did a PowerPoint presentation about this. It’s just this crazy, three-person life that I have to live for my whole life. Where when I go out in public, normally I’ll be wearing a scarf. I have beautiful scarves, different colors, I wrap them certain ways. The whole scarf-wrapping has evolved over 10 years now, so I wrap it differently. I feel like one person when I’m wearing the scarf, because people will either think that I’m trying to be fashionable –because the scarves are really in fashion now –or they think I have cancer. But never alopecia, because not a lot of people know about alopecia. I have gotten the nickname of “the scarf-girl.” Some women come up, "Oh, I love how you wrap your scarf. How did you do that? You’re so fashionable." The negative aspect of the scarf is that people think I have cancer, and they ask me, "Do you have cancer?" One guy was like, "Oh, how is your treatment going?" And people are just very curious, overall. It’s frustrating, it can be overwhelming at times.
>
> The other person, the part of this tri-life, is me when I have my scarf off. I usually will do that at home. Right now, I’m at the house I don’t have anything on. And I have lost 90% of my hair, but I still have some hair that I’m holding on to. And when I go to the beach I don’t wear anything, so I’m constantly getting stares, people are whispering, some people will come up and ask me if I have cancer. People, little kids - you know how kids are. Like my little cousin was over today and he saw me without the scarf, and he said, "Your hair is weird."
>
> The other person that I am is when I have my wig on and I have my makeup done, and I’m dressed to the T. And I’m getting all of this attention, especially from men checking me out, and it boosts my confidence. I’m getting positive attention when I’m all dressed-up with a wig on. I’m getting curious, negative attention when I don’t have anything on my head. And then with the scarf it’s like in-between; I get positive and negative.

What’s interesting about Sienna’s description of these three presentations is that nothing within her shifts. She suggests she is not doing anything differently, aside from changing her appearance. The three selves come from the different ways people react to those different appearances. She alternatively experiences rejection, curiosity, or interest.

Participant 2

The Life Story

Summary. For Halle, her experience of AA has the meaning of a major change. Her relatively untroubled life before AA is suddenly altered when she is 14 years old. Her awareness begins as an initial fear that the hair loss could be a symptom of recent injuries. While a diagnosis of AA puts the fear of larger health problems to rest, she struggles with uncertainty. Halle feels disheartened as she had never before felt there was no solution to a problem. The tone of her life becomes somewhat more melancholy, and her propensity for being reserved increases. Each time someone noticed her AA, she doubled down on her efforts to keep it concealed. She tells few people about the AA, and the act of telling – when there seem to be no other good options – feels confining, almost like being held hostage. Still, much of life goes on as usual – she participates in cheerleading, has boyfriends and good relationships, goes to college, and even studies abroad. In graduate school, however, Halle’s hair dramatically thins and falls out. She retreats to the safety of her parents’ home for the summer, and then to a relatively solitary life as a student. In some sense, Halle’s life stops. She is gripped with social anxiety, and becomes a self-described hermit. From here on out – including after the hair unexpectedly regrew – the effect of Halle’s AA on her life is even more pronounced. Her entire life is redefined, and every choice in her day – what she eats, when she sleeps, what she wears, how she interacts with others, the time she spends with friends – is all carefully planned to ward off or prepare for future worsening hair loss. Still, she is not angry with any of this. Given the AA might have been passed down by a beloved grandmother, her love and gratefulness for everything that grandmother passed down transcends anger or regret.

Detailed description. Halle explained some aspects of her youth that may be important in considering her reactions to her experiences with AA.

I don't remember being super sick as a child. I remember being fairly happy.

> I was in high school. Obviously, that's stressful. I went to an all girls' Catholic high school in California. But I don't remember being exceptionally stressed.

These brief statements suggest that Halle's youth was generally free from concern or unusual stress. She was able to live somewhat unaware of her appearance or health.

When the AA begins for Halle, there is a fear that it might be a sign of something worrisome. While many aspects of the experience have now disappeared from her memory, she remembers a particular conversation with her father.

> I was like 15 and a half, and a sophomore in high school. I actually remember it very distinctly. My dad was driving me home from cheerleading practice. And I had a spot – I don't remember where it was – but I remember it was mid-November. As my dad was driving me home, he said something like, "After the holidays we'll get an appointment with someone." And I said to him, "I'm not going to be comfortable until I know what this is." I was distinctly aware that something was wrong. A year before that up until the alopecia, I had two or three head injuries while I was cheerleading. Even to this day we don't know if that was some sort of trigger, because nothing else really had changed. I do remember it was mid-November. So I guess now this coming November will be 14 years! I don't remember the hair falling out. I don't remember what it looked like or how big it was, the spot. I just remember talking to my dad.
>
> I was thinking to myself, "I won't be able to enjoy the holidays," "I won't be able to focus," and "I won't be able to move on." My dad was

> implying, "I'm sure it's nothing." He wasn't being blasé about it. He was thinking that it really was nothing, and that it wasn't something that we needed to go to the emergency room for.
>
> I felt uncomfortable not knowing what was going on because I was a fairly healthy person. But I was having trouble cheerleading. I was getting hurt a lot. I was getting nervous. There are always those horror stories in cheering. Like a girl was doing a tumbling pass and hit her head, and then never walked again. That was always in the back of our minds that we need to be really safe and careful. That was where my underlying subconscious fear was.

Halle transitions over the past year from healthy and unaware of her body, to being concerned for her health. So concerned that she feels unable to think about anything else.

Halle's concerns changed from worry about health to uncertainty and fear of the unknown when she learned the reason for her hair loss.

> Within maybe that first year or two, I remember seeing a male doctor who was a dermatologist. I remember the interactions being so incredibly painful that it was just too much to bear. I think I felt very, very disheartened, and very scared and nervous. There was a lot of fear of the big unknown. I had never met anyone with alopecia. I had never heard of alopecia. I didn't really know what could happen. I don't remember, but probably at the time I was thinking like, "What is it going to be like with cheerleading?"
>
> I remember seeing another dermatologist within maybe a year or so. And she was very sweet. I do remember her implying there was really nothing I could do. And that there is medicine, but this was a life-long thing. I don't think I grasped that it's something that's not going to turn off. It might go to sleep, but it's never going to be fully off. I do remember trying to deal with that. I was disheartened in the fact that there was nothing I could do. This was maybe my first time of really feeling or thinking, "I don't got this." My parents were so proactive, and I try to be fairly proactive. It wasn't like, "Oh, we can just go to Stanford, or we can just go to UCLA or John's Hopkins." It was, "There is no option besides the medicine." And that's just placating the problem. It's really just putting the problem on ice. It's going to come back.

Fear of the unknown is accompanied by Halle's realization that her family's strategies for solving problems – being proactive, seeking expert opinions – would be inadequate in the face of this new and unfamiliar diagnosis.

Back at school, Halle was now having social encounters in which her peers noticed her hair loss, in effect increasing her awareness of her AA.

> I think it was my sophomore year. It was probably 6 months later I had a spot on the crown of my head. A girl who I went to high school with asked my best friend if I was anorexic because she noticed my bald spot. She thought that only anorexic people lose their hair. That was the only time I've really heard people ask questions kind of to my face. That was obviously really, really hard.
>
> I was offended. I was upset that she had noticed. She told my best friend, and my friend obviously told me. I was so upset, I think because I thought I had been doing a good job covering it up and I guess I didn't. My fear, my anxiety was, "If she noticed, who else is noticing?" That was a stupid comment. It did frustrate me. For her to say something like that was obviously rude. But I think that was probably one of my first times of being like, "I need to do everything I can to cover this up." It was more of a, "I need to be more diligent just about really checking everything."

Halle responded to the comment by feeling hurt. To prevent future offensive comments, she decided she needed to work harder at hiding her AA. For Halle, high school was not perceived as a safe space to reveal her AA because of the potential for hurtful comments.

Disclosing about the AA was another challenge for Halle in high school, and situations with mandatory disclosure were experienced with extreme distress.

> It must have been my junior year. I had lost the hair at the nape of my neck, and my coach for a competition had asked that our hair be worn really, really, really high in ponytails. I remember just feeling so uncomfortable. And actually, I wonder if my coach had it? Because I remember telling her, or telling our team mom, "I can only put my hair up this high," at a certain height. And it was going to look different than everyone else's. And I remember one of them saying that they couldn't see anything and it was going to be fine. I don't remember if they had said either one of them had dealt with it. I don't remember, but I do remember that happening and having to tell some of my friends in cheerleading,

> "This is why my hair is not very high." And all of them were like, "Oh, I‘ve never noticed anything." And I just remember being like, "Are you kidding? I deal with this 24/7. I’m thinking about it all the time. How have you never noticed this?" I feel like I’ve had a lot of people over the years be very kind, and I know they have lied to my face. It’s interesting the way that other people react to the alopecia versus someone who actually has it.
>
> I don’t want to ever share that I have alopecia. There for a while in high school, I could count on one hand the people who knew I had alopecia. I kept it so close. I didn’t want to tell anyone – I don’t know if that’s a defense mechanism. So the idea that I had to tell them, I felt like I wasn’t being held hostage, but practically, to be melodramatic, practically being held hostage by this. But I had to tell them, it was either look different and get scolded for not doing my hair correctly, or just tell them. And of course they reacted quote-un-quote properly. They were not angry, it wasn’t a big deal. It ended up being fine.
>
> I had told a few friends in cheerleading. There is a girl who would stand behind me to essentially catch me if I fell. And she stood, I mean like right up against me. Very, very close. And I do remember telling her about the base of my neck and whatever. And she was like, "Oh, I didn’t notice anything. Seriously, you’re fine." And to this day I remember her reaction and feeling like she wasn’t that good of a liar.

Halle’s carefulness with whom she told about her AA mirrored the carefulness with which she covered it.

Halle’s strategies for managing the AA – concealing it and using medical treatments to stall its expansion – were a part of her new routine throughout high school and beyond. Notably, in contrast to everything she said about the difficulty of her experience with AA in high school, she reflected that practically the AA was easier to manage.

> Honestly, through high school and college I really didn't deal with - I mean I dealt with hair loss. I went four months studying abroad not getting the injections. Other than that, I’ve gotten injections once a month for, I guess now 14 years. I don't remember a time when I didn't need to have injections. Maybe there was a time here and there where I would go

> maybe every 6 weeks or every 2 months. But I’ve been seeing doctors, I mean, I can't even remember all the doctors that I've seen for this. And so it was through high school and really college, it was always like a quarter-sized patch, never more than like one or two at a time. Now looking back, it was really quite manageable.
>
> I remember throughout high school having to really learn how to change my hairstyle. And I do that to this day, changing my hairstyle based on my alopecia. I don’t know many people my age who are every month or two parting their hair on different sides. And I’m always making up some excuse or some reason. People, like some girl friends will say, "Oh, your hair is parted differently today. Why?" And I’ll be like, "I just want to try something different." That’s total bullshit, because I’ve lost so much hair on one side versus the other that I need to cover it up. So it’s hard.
>
> Even now to this day, I have a mirror that’s probably 6 or 8 inches. A square, 8 inches by 8 inches that you get at Walmart or something. I have one of those in my office. I travel with one. I have two here at my apartment. I always have them because I’m always checking my hair from every different angle just to make sure that everything is covered as best as can be.
>
> It was after college, and I was getting my haircut. My hair was thinning, rapidly thinning. And my hairdresser introduced me to this dry shampoo that has a color tint to it. I spray it directly on the spots to cover it up. It’s not like a miracle worker, but I do remember feeling like it was some sort of - again, not to be melodramatic - it was some sort of saving grace that I had found this stuff. And now to this day I buy two or three at a time. My biggest fear is that I would really be up a creek if they ever discontinued making that stuff. I don’t know what I would do. Literally to this day I don’t go anywhere without it. I’ve got, again, one in my office. I travel with one. It’s those kinds of things. I’m constantly doing anything I can to make sure my hair is in place. I never wear my hair down ever, and I just always make sure that it’s as covered as possible.

In addition to the medical treatments, changing hairstyles, and tinted shampoo, Halle introduces making excuses as another strategy for keeping knowledge about the AA private. These strategies and other encounters with AA might have taken a toll on Halle.

When confronted with other adversity combined with the distress of AA in high school, Halle looks to her peers – perceiving them to be living blissfully unaware of their bodies and other troubles.

> I remember having a tough time my junior year, really having a hard time with it. I maybe I felt it was the worst it could be. I remember being at a competition and being very, very upset. And telling two of my girlfriends that I was essentially jealous of a teammate of ours – a friend of mine even to this day. I was jealous of her because she seemed to have everything going for her. And that was hard. That was hard. I had broken up with a boyfriend. I remember being at this competition and just kind of being jealous that she didn't have to deal with the alopecia and all these other high school things.

The setting of a cheerleading competition provides a stage with which Halle perceives others as having freedom from concern. She seeks and receives the consolation from friends, which is somewhat in contrast to her increasing tendency to withdraw.

> I've never been a super, crazy, outgoing person. I've always been a little bit reserved. I've always been personable, but I'm the I-never-want-the-attention-on-me type of person. I'm very happy just kind of sitting in the background. I remember feeling kind of very – I guess maybe melancholy is the right word. Feeling very just unsure of myself. I'm sure much of it was the alopecia. That being said, I was 15. I don't know whether I would've felt a different way had I been 35. Part of those feelings could've been a byproduct of my age.

Withdrawing from others provides safety for Halle; less attention means less potential for the AA to be noticed. Halle's low point was somewhat transitory.

Halle explained during college she had a brief period in which she experienced the freedom from stress, AA, and associated medical interventions that she envied in her high school peers.

> I studied abroad in Egypt. It was always sunny; I was always outside. It was actually really hot. I was eating random foods. Class really wasn't stressful because it was really easy. I didn't have any money stress because money there is like monopoly money; it's really cheap. Every weekend it was like, "Oh, let's go to Alexandria!" Or, "Let's go to Cairo!" And my friends and I would just do that. We had no cares. I really didn't go to class much. There wasn't a care in the world. Not a care in the

> world. I can easily mark that as probably the happiest time in my life. Ten years later I’m still very, very close with my friends from study abroad. It was the only period in my life I didn’t have to see a doctor because I didn’t have any stress, so I didn’t have any hair loss.

This time period stands out as a clear and distinct time without any AA. Freed from her concern about concealing her AA, she connects deeply with others unencumbered.

Halle’s connection to others during this time extended to intimate partners. She explains:

> I remember telling my boyfriend in Egypt. I remember him reacting probably the best, quote-unquote. When I was telling him, he would ask me, "What do you do? Do you go to a doctor? Do you have to take medicine? How frequently?" He was interested in more of the details of it. Where other boyfriends would be like, "Oh, okay. Whatever." Not dismissive, but not like it was a life changer.
>
> I had boyfriends. I had good relationships with them. That was always fine. I remember always telling each of them. They always reacted fine. It was never really an issue. But I remember always feeling that it was something that opened me up more to people any time I told them. But it never, has ever changed a friendship after I tell them.

Halle finds it especially supportive when a romantic partner showed interest in her AA and how it affected her. Sharing about her AA generally made her feel vulnerable. Perhaps similar to her father when she first developed AA, some boyfriends were not blasé or dismissive, but maybe did not grasp its importance at the time.

When confronted by increasing hair loss, Halle retreated to safe spaces and relationships. Yet there was no escape from the uncertainty and the reality that this was her “norm.”

> It didn't get bad until I was in grad school. Maybe 4 or 5 years ago. That's when the alopecia itself was really bad. I started to lose a lot of hair and it was thinning. It wasn’t so much patches, as it was thin areas. Then I did lose all my hair. So, there for a while, I didn’t have any. And I ended up

actually wearing a wig for a year and a half. It was definitely hard. I didn’t know what was happening. I didn’t know what was going to happen. I didn’t know when it did actually happen. The fact that I actually did have to wear a wig – I don’t think I was really, fully accepting it or acknowledging that it was my norm. I really don’t think I was fully accepting it.

It was hard emotionally. Everything was hard. Everything was very hard. I didn’t want to socialize. To this day I feel like I lost my early 20’s. I have a lot of friends who will say, "Oh God, my early 20’s were so fun!" I was inside reading. I moved home for a while. The summer between my first and second year of grad school, I moved home. I didn’t stay in New Jersey like my other classmates. They all stayed in New Jersey and got internships and all that fun stuff to advance their careers. I went home and I lived with my parents. I didn’t do much, I really didn’t. It was very, very hard. I think I was just in a constant state of sadness.

I was like a hermit. I didn’t want to go out. I didn’t want to socialize. I had very, very, very severe social anxiety. I was always assuming people were talking about me or looking at my hair. I had a woman one time in church, a very kind older woman who I didn’t know. She leaned over and she said, “How do you get your hair so shiny?" I was just distraught. I excused myself, and I told my dad I was going to go to the bathroom. Then when I didn’t come back for more than a few minutes, he knew that I was upset. She obviously didn’t mean any malice, but it was very hard.

I wasn’t ever really around other people besides my family. I didn’t even want to see my extended family. I was just around my parents and my two younger sisters, and even then I didn’t take my wig off around them. I wasn’t ever around them without my wig on. So that was very hard. I don’t want to sound angry - but until you have worn a wig, you don’t really understand. Like in the morning, you want to just go downstairs and grab a cup of water before you start your day. Normally someone would just walk downstairs not even batting an eye. I would put on my wig, and then walk downstairs. I was trapped. I was absolutely trapped in this situation. And it was very difficult. I didn’t know when it was going to end. I didn’t know if I would ever get better medically. I didn’t even know if I would get better emotionally. I was wondering, “Am I going to live with my parents for the rest of my life?” I didn’t know. I didn’t know what was going to happen. It was very hard.

And there is a multitude of things that you just don’t even realize. Like when it’s hot out, your head doesn’t breathe and sweat like normal when you’re wearing a wig. It’s trapped in there. So you can’t really do anything

> outside when it’s really, really, really hot. Because then you’re uncomfortable, and then you’re sweating. Or you don’t go swimming. And where I’m from, we literally swim year-round. So you’re not swimming, you‘re not running, you’re not doing yoga. These wigs will come off. Everything I loved to do was done. As I knew it, my life was over.

She repeats, “I didn’t know,” re-emphasizing the uncertainty and powerlessness she continues to experience. She withdrew deeply. Her world shrank as she found fewer and fewer spaces comfortable, eventually only feeling comfortable without her wig when no one – not even family – was around. In retrospect, her time with the wig is time she was not living; it was time lost.

Despite not knowing if she would live the rest of her life with her parents, Halle managed to return to graduate school. She does so aided by an improved wig and the support of others.

> I wore one wig for a little while. Then I wore a second wig for maybe another little while. And then for the last 6 months I wore a wig that was just a life changer. It was really nice. It was very, very expensive. I’m very lucky that I have parents who will support me that way. It was very expensive. It made me feel a little more confident. Again, I don’t think I ever fully accepted that I would wear a wig for the rest of my life.
>
> When I was in grad school and I was wearing a wig, I saw a therapist there at the school for about a year. There were a lot of issues I was trying to work through. But, it really was trying to figure out what is the worst-case scenario. Because there was always fear. I was wearing a wig. I was always, always, always afraid people were staring at me because I’m wearing a wig. And they don’t know why, and I don’t want to tell them. And they are never going to ask. I was working with her about what is the worst thing that can happen, and who would I surround myself with. My parents were also very, very supportive. It was helpful to speak with them, talk with them.

It was utterly uncomfortable living with the concern of being stared at or recognized for wearing a wig, and struggling with knowledge of the wig being known but unspoken.

Halle works with a therapist to identify the source of the discomfort, which she now names as fear. She elaborates on the meaning of this fear:

> I think it's just really opening myself up. I think it's kind of the fear of rejection. It's an interesting way of looking at rejection, wondering if, "What if I do tell this to someone and they say, 'Well now you're ugly'." It's never happened, but I can't imagine it won't ever happen. I can't imagine how someone wouldn't be grossed out by it. Because you only see bald people with cancer. And people think those people are dying. So how do you know? I don't.

The fear represented a vulnerability and a window for rejection.

Even as Halle's hair unexpectedly grew back to no longer needing a wig, she struggled uncertainty knowing that it might just as unexpectedly fall out again.

> I don't know why my hair grew back. I really don't. There was an inkling, there was like an ounce of me accepting the wig that I had. If I had to wear it for the rest of my life, maybe I could. And then my hair started growing back. So that's why now, every day since, if I notice a new patch or I notice my hair is going to fall out, it's terrifying. So I think the overall day-to-day thought and feeling about alopecia is constant fear of just not knowing. Could today be the day when I lose all my hair again and have to wear a wig? I don't know, I really don't know. And it's a constant fear. It's a constant, constant struggle. The fear of the big unknown has become a very conscious stream of thought with alopecia. There is a constant fear of more hair loss because you don't know what is going to happen. Because I've relied so heavily on the cortisone injections, for me it's wondering if and when the medicine will stop working. I'm not an idiot. Your body gets used to medicine, and then you need more and more and more until it says, "We're done." I think I have a fear that the injections will stop working. I have a fear that my hair won't ever grow back. I have a fear that I'll lose it all again. I have a fear that I'll have to wear a wig. A lot of fear. And I don't know if fear is the best word to be using, but that's really the only word I can think of.

The threat of more hair loss, no regrowth, and having to wear a wig was "constant" for Halle. Each new patch of hair loss was potential confirmation of her fear becoming true. Though she recognized that a part of her had become okay with the wig, clearly it was minimal in comparison to the seemingly overwhelming magnitude of her concern about wearing a wig again.

Halle asserted that it was a pivotal experience when her hair loss dramatically increased and she started wearing a wig; moving forward she was a changed person. Halle identified this change as the meaning of her experience with AA.

> I think that I definitely view my life as before the wig, and after the wig. I'm a very different person. I try to be a positive person. I try to look at everything as the glass is half full, which is hard to do. I try to recognize that, yes, I was essentially an asocial hermit for two years. But I also got a lot of extra time with my parents that a lot of people don't get. I experienced therapy for the first time. It made me a very studious person. I wrote my thesis essentially because I was by myself; I was very focused on that. I think it [alopecia] does define me. I hope that it doesn't, but I don't know. When I'm on my deathbed I hope I don't say something like, "I wish I had done more and not cared about the alopecia as much."
>
> I think about how the time when I was wearing a wig - I'm now a completely different person than I was before. I was much more carefree; I was much more go-with-the-flow. And now I'm so rigid and type A. And I'm always preparing for everything because, I can't just be a person who is late for work so I'm just going to grab a sandwich for lunch. I can't do that. I don't eat gluten. I don't eat dairy. It inflames my body, which will then lead to hair loss. So, I'm cooking all the time. I'm preparing every meal. I just don't want to take that chance. So the time in-between wearing a wig and when it really started, I don't remember much other than being a totally different person.
>
> I'm not a drug addict. I don't have family members who are drug addicts. But I do kind of wonder sometimes if there is any comparison to the way that someone who is a drug addict is always thinking about when they are going to get their next fix. I'm *always* thinking about it. It's never not on my mind. It's like I'm sitting there having a conversation with a colleague of mine, and then I kind of like play with a few strands of hair and one of them comes out. I'm right back to the alopecia. I'm *disconnected* from that conversation, talking about whatever. And I'm now thinking about the alopecia and getting worried about it. But it's something that I don't know anything else. I don't know any other life. I don't know any other situation.

The fear of more hair loss pulled Halle out of the world, out of time, out of social interaction. Everything has become mediated through her AA. Halle has tried to focus on the positives, but ultimately the moment she started wearing a wig seems to be the end of her innocence. It was the end of not being preoccupied by concern about more hair loss.

Halle's attempts to guard against the threat of increasing AA seemed to take charge. She started following carefully prescribed plans to identify and reduce whatever factors might lead to increasing AA.

> I think about it all the time. My alopecia dictates every part of my life. I can't think of one part of my life it doesn't dictate. It dictates what I eat, what I don't eat. It dictates how much sleep I get. It dictates what alcohol I drink. It dictates how I wear my hair. It dictates when and where I exercise, and how I exercise. It dictates how I dress and how I wear my hair to work. It dictates how I deal with people on a daily basis. I'm always, always, always trying to eliminate as much stress as is possible. It dictates the way I use my personal time at work. It dictates everything.
>
> I would say my alopecia comes from maybe 40% stress, 40% diet, exercise, and sleep – that kind of stuff – and I think that 20% sometimes is just the uncontrollable. But sometimes, very, very, very unfortunately, I'll lose my hair and I'll know exactly why. I'll know exactly why. I lost some hair in March of this year, and I remember I had a very tense week in February with one of my coworkers. I remember not being able to control it, not being able to react properly, and not being able to leave it at work. I brought it home, I was stressed at home, and then a month later I lost some hair. I wasn't surprised whatsoever.
>
> And so just the other day one of my coworkers is being a complete asshole. I was talking to a friend of mine. She was like, "You should really say something." And I was like, "You know what, I know when I need to pick my battles. I know when I need to de-stress myself. I know when something is worth getting worked up over. And this is not something worth getting worked up over." I don't know if that's something that's just a by-part of being at my age and working now for 10 years. But it's kind of like, I do pick and choose the way I interact with people based on my stress level. If something is going to get me so worked up that I need to take an anti-anxiety pill. If it's going to get me that worked up, then I need to say something. I'm trying to not use the anti-anxiety medication as

> much. But then the other day another coworker of mine said something really quite nasty, and because she is a nasty person, and I was like, "You know what? That’s not for the office." I did say something as her supervisor. I needed to instruct her on that. I could have let it go, but in terms of our work environment and our company it was something I needed to address. But each and every day, I don’t want to be stressed. My boss can be a stressful presence. I try to mitigate getting stressed by working with him. I try to be as prepared at work as possible so when he comes at me with a few different questions I’m prepared. Then I’m not stressed, so then I’m not taking the anti-anxiety medication. I’ve always got the alopecia in my mind.

In addition to lifestyle factors, Halle continued medical treatments in hopes of minimizing risks of going back to wearing a wig.

> I went four months studying abroad not getting the injections. Other than that, I’ve gotten injections once a month for 14 years now. I don’t remember a time when I didn’t need to have injections. Maybe there was a time here and there where I would go maybe every 6 weeks or every 2 months. I think it’s hard. It’s painful. It’s very painful. But, I’ve welcomed the pain because if it’s going to work, I’ll do it for the rest of my life.
>
> I do also take prednisone, which I try to minimize. I’ve taken 5 mg of prednisone every day for probably 2 or 3 years. My doctors are trying to get me to decrease that. There is another example of how the alopecia affects every part of my life. Every year I go to get my eyes checked, and every year my doctor tells me my eyesight has gotten worse, when at my age it should have stabilized. It’s getting worse because one of the side effects of prednisone is eyesight decreasing. For me, it’s kind of like, well what do I want? To wear glasses or have hair? At that point it’s a tough one. I’m at this point, every year I go in, every year I expect to see it has gotten worse, and every day I take the prednisone. It’s a Sophie's choice.

The AA takes on additional meaning knowing that Halle has continued medical treatments despite risks to her functioning. For Halle, hair loss and wearing a wig, when compared to decreased vision, are seen as much worse.

Halle even uses the way she interacts with others to manage her experience with AA:

> I’m like my law firm's one-woman welcome committee when we have new people start. I’m very, very welcoming. I think it’s because I want people to remember me and think of me as welcoming and interesting and communicative, so they don’t even maybe possibly think that I have alopecia. You know how you meet people and maybe they have a scar on their forehead, but they are so funny you never remember the scar? I think that’s kind of my weird way of thinking about it. Trying to control the situation.

Considering the possibility of a negative reaction if someone were to discover her AA, Halle has endeavored to create a lasting positive opinion of herself and regain a degree of control that she fears she might lose.

While doing whatever she could to minimize the threat of further hair loss, Halle simultaneously made plans for a potential future in which her hair loss increases.

> In years past I’ve not been the friend I’ve wanted to be because of my alopecia. I’ve missed birthday parties, and pool parties, and just outings in general because of my alopecia. Besides the fact that I didn’t have much of a social life in grad school. Even when I was living at home while I was wearing a wig - my best friend wanted to go to dinner for her birthday with her parents and like 3 or 4 of her other friends. And I said, “No” because I couldn’t face them all. That’s the worst. It just makes me so upset. I never really talked to her about it. It’s a minor miracle that my friends have not totally disowned me. For a year I was just not a friend to them – at least a year. Now I’m trying to make up for that time, which is hard to do when I live across the country. My same friend, she’s turning 30 in a few months and I’m making it a point to fly across the country for two days. I’m not missing this. Because I don’t know if next year when her birthday rolls around, if I’m going to be wearing a wig or not. I don’t know that. So I need to really take the time now.
>
> My family was in Mexico in June, and I went swimming in the pool and in the ocean, everywhere. It was the first time in a very, very long time that I didn’t have a lot of hair loss, to the point where I could actually go swimming in public. I just lived in the pool and the ocean. And my parents were like, "God, get out of the pool." But I didn't want to because I didn’t know if I would ever have the chance again. It’s because of those things that I’m always thinking of it.

Similar to how someone might want to take advantage of every opportunity for fun in the last days of summer, Halle has been taking advantage of opportunities to be free and without concern with the expectation that the opportunities to do so may be fleeting. She recalled feeling unable to face important people before, and expects she might feel that way again.

In the midst of guarding against and preparing for a future of greater limitations, Halle was introduced to the idea of living life openly with AA at a NAAF conference.

> The type of people I met at the conference – they didn't care if they were bald or wearing a wig. They wanted to go and do everything. And me with a full head of hair I was still, I was the most self-conscious one.

Halle seemed to recognize a potential contradiction between her extent of AA and the potentially overwhelming concern she has about it. While not revealing her physical appearance with AA, Halle opened herself to potentially share her AA identity to acquaintances.

> Something that has changed. Since the conference, I want to be more involved with NAAF. Even going around on the day at the conference where we go up to the hill. We were doing legislative work, lobbying work, essentially. I have a lot of friends who work on the hill, so I was nervous they were going to see me. See me in this shirt and see me with people, and be confused. But I was kind of like, if I see them and I tell them, then that's their problem if they react negatively. So I don't know what I hope for the future. I hope that I can be a little bit less strict with myself. But I don't know. I guess we'll see.

Halle started to take steps to out herself, to allow for the possibility that others would find out about her AA, because she has perhaps identified a cause more important to her than her concern. She stopped short of making a declaration to friends, however, instead leaving it to chance should she be discovered. As she reflected on her potential future, she noted she expects herself to continue keeping the AA from increasing, and continue keeping it private.

> I hope I can let it dictate less of my life. I don't really perceive that happening, because of this constant fear. If I figure out that if I'm not stressed and I eat a gluten free diet, my alopecia is okay – why would I change that? Why would I bring on alopecia if I don't need to? That being said, I also want to live my life. It's very, very hard, but I try to be a little more open with people, which I'm not doing a terribly good job. When I meet people, I just know if they are going to be understanding or not. I think in the future maybe I'll give people a little bit more of a benefit that they will be understanding. I would hope they would be.

Although Halle may have become tired of the ways her AA has restricted her life, she describes little hope for change given the strategies she uses (e.g., medications, stress-reduction, diet) provide a means of controlling her AA. Yet, her recent actions at the NAAF conference suggest her openness about her AA has maybe already begun to transform. Perhaps the reluctance to recognize that as a change is an acknowledgment of how truly difficult Halle expects it will be to continue that change.

The Typical Day

Summary. Halle's typical day is guided by her efforts to decrease distress about her AA. Some actions are inspired by vivid memories of despair in moments when she noticed increased hair loss. Some actions are dutifully done to minimize increased shedding. Other actions are done to limit others from noticing the AA. Still, she continues to take part in activities she loves – some that she felt unable to do during the year and a half when she was wearing a wig.

Detailed description. Halle explained her typical day involves a number of strategies to reduce feelings of distress that might occur were she to notice signs of changes to her AA.

> In the morning obviously I get up. I always put my hair up in a clip. I never wear my hair down. And that just might be a tic of mine. But you know when you wear your hair down and it all of the sudden is on the back of your jacket? I don't want to ever see that. It kind of triggers me, it makes me more worried. It makes me anxious. So, I never really wear my hair down. I put my hair up in a little clip, and I make a smoothie. I always just have a smoothie in the morning. I'm fairly healthy, and I try very, very hard not to eat gluten or dairy. So, I make a smoothie when I get ready for work. Concerning my alopecia, I actually never brush my hair in the bathroom. And I actually never brush my hair in one place. I walk around my living room. If you have ever brushed your hair in the bathroom and seen a chunk of hair on the floor, it's pretty traumatizing. So, I haven't done that in forever. I'll never have white tile in any house I ever buy. Or I'll just rip it out and change it.
>
> I walk around the room. I put my hair up. I either put it in a braid or a ponytail or, some kind of concoction pinned back in one different way or another. If I do wear my hair down, it's always pinned back.

Halle discovered certain spaces – bathrooms with white floors – or ways of wearing her hair might cause her distress. She minimizes the worry by avoiding them. She continues to take steps to minimize stress of potential changes in AA throughout the day.

> I'm never, ever fooling with my hair during the day. Or, I try not to because one day, one very specific moment in grad school I was sitting at my desk in my office. I was just putting my hair behind my ear, and the little hairs that were sideburn all came off. And in that moment, I had no more sideburns. So, I never, never do that anymore. I don't want to deal with that.

Halle decided certain behaviors are off-limits because of the potential for them to cause distress.

Another part of Halle's routine is making sure her spots are covered. She explains:

> If it's windy outside, or humid, or rainy, or anything of that sort, normally when I get to work I'll go to the bathroom with my extra mirror and I'll check it. I'll check my hair to see if anything has come out of place.

Hiding the AA protects her from the possibility of others at work knowing her secret.

Halle includes in her routine a number of strategies to keep herself healthy, and thus managing – according to her understanding of her AA – the likelihood of having an episode of increased hair loss.

> I go to work. I have a standing desk, so at least I try to stand half of the day. Again, I'm trying to be healthy. I drink a lot of water, which is supposed to be really healthy. I eat a pretty healthy lunch. If it's not too hot or too cold and my boss isn't there, I try to go to our roof and sit out in the sun for a little while at some point during the day, because apparently the vitamin D is helpful for the alopecia. Sometimes it's hard living on the east coast with winter, the idea of not getting enough vitamin D. I do walk to and from work, which is only like 20 minutes each way. So I think that gives me enough vitamin D some days. Anyways, I try to go up to the roof, just try to be calm. If I'm dealing with a particularly dicey situation, either with my boss or with my coworkers or whatever, I try to just be as calm as possible. I try to mitigate the situation.
>
> I always try to take a break from work even if it's just sitting in my office and reading the newspaper or maybe watching something on my computer for a little bit. I try to kind of disconnect from my work. My job is not hard in the sense that it doesn't take a brain surgeon. But, it can be stressful. Our law firm has a lot of big clients. So there is a lot of pressure on everyone at the firm to do 110% all the time. Most times I do feel like I can manage that, and I can keep myself organized. It's all about time management. So, with that I try to just try to stay calm. Sometimes my coworkers will be dealing with a case or something that's very, very stressful, and then that stress is just around me. It's kind of like, "Okay, I just need to go to my office and close the door," because they are all running around like chickens with their heads cut off. So, those are the things I try to do to just not get frazzled. And not get worked up about everything. Which is easier said than done.

In addition to reducing her own stress, Halle's experience of AA has led her to have greater empathy for co-workers.

> I try to be as understanding – I feel like because of the alopecia, I try to give people the benefit of the doubt as much as possible. Unless they

> really burn their bridges. Because I don't know what they are going through. If I do have a bad doctor's appointment or my head is sensitive due to the injections, and I'm snapping at people. I just try to close my door and not talk to people. I don't want to have to explain myself.

She wants to be understanding of others, hoping they might return the favor if needed.

Halle explained her routine after work continues to include actions to reduce potential hair loss, and taking steps to not overwhelm herself with distress if more hair loss occurs.

> Then I leave work, obviously. I come home. However, my hair has been throughout the day, I always normally take it out and then put it back in a clip. I try not to wear my hair in a ponytail too much because I know it's bad for your hair.
>
> I don't wash my hair much; I probably wash it once every 3 days because the tinted dry shampoo that I use sucks up the oils. And I just don't want to wash my hair, because when I wash my hair if I'm losing hair at that time, it's not a great feeling. Feeling your hair leaving you. When you're showering and you're losing your hair, the hair will come out, but it won't come out just in the tub of the shower or the floor of the shower. It will run down your leg. So you do feel it. It's very unfortunate; it's not just gone. You have to feel it leaving your scalp. So, that's hard. It's hard because there is nothing I can do. I have to wash my hair, but that hair is going to be gone whether I shower today or tomorrow. I'm going to lose that hair when I'm in one of those cycles, which I understand the cycles are spring and fall. I try to keep that in mind as well.

Halle has recognized that despite her efforts, there are some situations in which she has no control. For those situations she tries to keep the experience in perspective.

Halle sometimes takes part in activities she enjoys – notably some of them activities that she felt she was unable to do (e.g., yoga, going out with friends) during the time period when she lost most of her hair and wore a wig.

> I come home. I sometimes go to yoga. Sometimes I have to do other work for my job. Sometimes I read. Sometimes I watch TV. It kind of varies, if I go out with friends during the week and I eat dinner, I try to eat a healthy

> meal. I’m very conscious of getting to bed on time, because if I don’t sleep well, then I’m just not a good person. So, in terms of the alopecia, I think it’s pretty much always there. It’s always there.

Ultimately Halle admitted AA is a continuous presence in her typical day.

Halle finalized her description of her typical day by mentioning that sometimes she struggles with thoughts about how unpleasant it is to do so much to maintain her hair.

> I try not to go down that rabbit hole of, "Well, if I didn’t have alopecia, I wouldn’t have to deal with this." And it’s kind of like, “You know what? Get over it.” I do have alopecia, so I need to just deal with it as appropriately as possible.

Halle reframes that her routine is merely doing what needs to be done.

The Current View of Self

Halle explained she views herself as a somewhat anxious person who is affected by her experience of AA.

> I try not to think of myself as like some victim of alopecia or an alopecia patient, because it really is about me. It’s a part of me. It’s something that I try not to think of as a defining characteristic, even though I know that it is.
>
> I don’t know how I would describe myself. I don’t think I would describe myself as exceptionally happy. I think I’m a content person. I know some people who everyday come in with this big ass smile on their face. And I’m not always like that because I think I’m fairly, I wouldn’t say cynical, but I think I’m anxious. I think I’m always nervous about what could happen. I also do try to keep in perspective that while I do have alopecia and it’s incredibly life-altering, I don’t want it to be life-defining. But it’s something I deal with.

Halle again emphasizes her AA has altered her life in important ways, but puts forth that she hopes it does not define her or make her a victim.

Despite the stress and distress she experiences with her AA, Halle asserts she feels no resentment for having AA.

> I had a girlfriend a few months ago say to me – she also deals with her own health issues – but she says, "How do you ever just not get really upset about it?" Of course I get upset about it, but how do I not just get really angry? Essentially she was asking me, how do I not get angry with God that I have this? I was really taken aback by her question because I’ve never felt angry about this. It’s because there is a very, very, very slight chance – and we don’t know, and we never will know – but we think maybe it came from my dad's mother. My grandmother who was a fabulous person. I would never be angry or sorry. How could I ever be angry that this is something that was passed on to me? There are a million other positive things that have been passed on to me through my dad from my grandparents. So how would I ever be upset about that? This is just something I have to deal with.

She explains her perspective about her AA, recognizing the positive aspects – that she potentially has AA because of her strong connections with people who have inspired her character and showed her support.

Participant 3

The Life Story

Summary. Gabriella was already aware of AA when her hair began to fall out, as she had expected it might someday occur. The onset of AA for her began in the shower, with a sudden awareness that her hair is shedding more than usual. She acknowledged she knew what it was, and felt devastated. She was aware of subtle shifts after it began to fall out, for instance, how her softball cap needed to be readjusted to cover her spots. As hair loss increased she found hats which provided her a sense of security, and most people around her treated her the same as before. Her hair suddenly regrew and she felt pride, and an increased sense of appreciation for her hair. She explored the various ways her hair can be, relishing in the freedom to do so. Just as suddenly as before, in college, Gabriella noticed she was shaving her legs less often. She observed with distress the hair slowly shedding on various parts of her body one by one, until the hair on her scalp finally released. She again felt devastation, with concern about impacts on relationships and comfort in school. She found wigs and regained her confidence with them on, feeling like herself again. On occasion Gabriella ventured in public without anything covering her head, choosing comfort or important activities over her concern about others' reactions. Over time, she became curious about life without a wig. After experimenting by going without a wig in a new situation, Gabriella found acceptance and felt even more like herself. Having concern about how to disclose her AA to people who have known her with the wig, she ponders how she might make the switch. She reflects that she has maybe not been as aware of her emotions throughout her experiences with AA, and hopes to more fully acknowledge her experiences with AA in the future.

Detailed description. Gabriella learned at a somewhat early age what AA was, despite experiencing minimal hair loss at that time.

> The first time I had alopecia. I guess I always knew because when I was 7 I had just this really – it was bizarre because my nails were really thick and gross. My mom took me to a dermatologist. She couldn't figure it out, went through a whole asking a bunch of things and finally said, "Do you have patchy baldness?" And my mom was like, "Yeah!" I had just this tiny bald spot on my head. So she instantly knew it was alopecia. I actually went to a dermatologist who confirmed that. From there my patch went away instantly. But I had always been told that, that the likelihood of me losing my hair is possible, and probably likely.

While this experience brought about minimal change for Gabriella at the time, her learning that AA was possible – maybe even probable – would be important.

The start of Gabriella's first episode of noticeable hair loss came into awareness abruptly, and in an "instant" she knew what it was because of the experience with AA in her youth.

> I was probably 14. I think I was in the shower and realizing that my hair was coming out more than normal. With the idea that I already knew that it could happen – it was kind of an instant, "Yeah, I know that's what's happening." I know I sat there and cried in the shower. I didn't know really how to react. But that was how I did react. I think there was this devastation that it was happening. But then at the same time, maybe my religious background kicked in and said, "You know what, I'm strong. God gave me this because I'm strong, so there's a reason I have it." It was so long ago. There is not much that I totally remember, other than what my first reaction was and crying, and thinking "Why me?" I know it was a long shower. But then also, there was the thought that, "Okay, maybe it's not?" But that didn't last long either.
>
> Then I got out of the shower and told my mom what was going on, that I thought I was losing my hair. Honestly, I really don't remember much about that conversation other than, "Mom, I think I'm losing my hair. Can you see if you can see any bald spots?" That sort of thing. I don't even remember if she could see anything at that time or what she thought about it. You really don't want to remember those things.

Gabriella recalled rapidly passing through various reactions in the moment in the shower – questioning, uncertainty, denial, devastation, and searching for meaning. She did not want to remember this experience, suggesting it might be a painful memory.

Familiar activities in Gabriella’s life began to draw her awareness in new ways as her hair was shedding.

> At the time I was playing softball. Every summer, it was about that time of the year, July I think. I remember wearing a baseball cap and then I'd have to put on a helmet to bat, and I just remember playing softball and being conscious of a lot of hair falling out into the helmet. Or my hat not staying on straight, and I’d have to straighten it to cover up what's going on.

Gabriella began seeing visual evidence of her AA and started making adjustments to keep her spots concealed.

As the hair loss became more profuse and her time around peers increased, Gabriella and her mother searched for something to cover the AA at school and provide a sense of “security."

> At school I figured out I was probably experiencing quite a lot of hair loss. My mom took me to the mall to get some hats, because that's what I was interested in at the time. And because hats weren't in style for girls, women especially, we had a really hard time finding them. I remember shopping for those. I probably felt desperate because, like I said, it didn't seem like we could find any. And I don't know that I even knew about wigs or what that meant, or anything like that. So I felt just desperate to find anything to try to cover up the little bit of hair I had on my head. I felt desperate and worried that we wouldn't find anything.
>
> I know I found one light blue kind of baseball cap that was more kind of girly that I bought. My mom got me kind of a dressy, like a more cute one for school pictures. I know that I was fortunate in school they allowed hats at the time. I remember wearing hats to school. Wearing hats meant that I'd be able to have some form of security. Even if it wasn't much, it was something. It made me feel a little bit better. Just that security feeling.

By using the word “security,” Gabriella seems to suggest that having the AA exposed would feel unsafe, or at a minimum uncomfortable. Covering the AA gave a peace of mind, and she became accustomed to the security. Only a few situations threatened it. One example is school picture day.

> My school class picture was a big deal because I just had these little strings of hair. My mom said, "Go and wear your hat." I was like, "But they don't allow hats for school pictures." And she's like, "I don't care, you're wearing a hat! Just tell them that you are going to wear your hat." And so I showed up and the photographer said, "You can't wear a hat." And I'm kind of a goody-good, and I'm a rule follower, so I said, "Okay" and took the hat off. And the guy looked up and he's like, "Oh my God, do you have cancer or something?” And I'm like, "No, I just have alopecia, I just don't have any hair." And he's like, "Oh. Put your hat back on." So I put my hat back on, and I was the only one in the yearbook with a hat on for their school pictures. When you get the yearbook and you look back and see that you're the only one, you kind of feel singled out. Like, "Why did she get to wear one but the rest of us couldn't?" But no one ever made a comment about it.

> It was the way I had been. I had gone to school that way, that was how it was. It was a natural thing, but I know that it was a big deal that upset me that I couldn't wear my hat. And my mom's telling me, "You just tell them you're wearing it." And then of course I did. But it worked out.

It was upsetting that she would be exposed and not in her “natural” look. Even though she got the outcome she desired and could look natural, she still felt somewhat “singled out” for looking different.

Most friends and peers treated Gabriella no differently with her hat, with one rare exception.

> I think I was kind of lucky that I had a lot of chill-out friends, just because I was involved in music and band and what not. And no one really asked. I think they all kind of knew what was going on. And honestly, I don't even remember if we ever had a conversation about it before or anything, because I don't know if any of them ever wondered really what was going on. But I think one or two of them knew; I think I had mentioned that I had this possibility that I could lose all my hair. And they just kind of knew that's what was going on. We never talked about it. I just hung out like normal with my friends. I was very happy that besides all the people at school, no one ever really bothered me except for this one girl in my home ec class or something. She knew that something was going on and she kept making all this, "Why do you wear hats every day? Why do you wear hats every day? Why do you wear hats every day?" And I was like, "Because I want to, because I want to, because I want to, because I want to!" That's kind of the only time anyone ever gave me a hard time. Most of the time everyone pretty much left me alone.
>
> Hearing stories from other people with alopecia, I just find myself really lucky in that respect. Because I just wore hats to school every day. And I think I had enough stringy long hair for a little while that no one really noticed all that much. I think people knew or noticed, but they didn't pick on me or anything like that a whole lot.

Gabriella might have stood out among her peers because of her hats. Despite this difference, she encountered very minimal extra attention.

Even though she experienced relatively few negative reactions from others, Gabriella’s description of how she felt when her hair regrew reveals she might have struggled privately with not feeling good about herself at that time.

> I remember for Christmas band concert, it was my freshman year and I was so excited. I was able to not have to cover anything on my head nor have to show up bald or anything, because it had grown back to this cute little pixie cut. I have the picture of me in my little band dress and my hair all really short. I had that really great feeling of feeling good about myself again. And proud to be who I am.
>
> I can't even say I could remember it growing back in. Having it now, again, after not having it for so long, every once in a while I try to remember what that felt like. I guess because I want it again so bad. But before it was that euphoria that excitement, that like, "Hey, it's coming back!" But at the same time that apprehension that, "Now wait a minute, this could be a false call. It could come right back tomorrow, or even in a year or two or ten." So yeah, just being happy in the moment, excited that it's finally coming back.

Amidst some uncertainty and hesitation, the regrowth brought about a change in how Gabriella felt about herself. The feeling of pride contrasts with desiring security when her hair initially fell out. Her feelings about her hair had changed following her AA as well.

> Once it started to regrow, I think I went to prom that spring with a friend who was older. I had slightly longer pixie cut hair; it was really cute. Then I grew out my hair, and I grew it out and grew it out and grew it out until it was really, really long – right before my senior year in high school. It was really long. So about three years later, I had it very long. I don't think I had ever had my hair that long before but I was like, "I'm not cutting it ever again! It's too valuable!" I had it really long in all my senior class pictures, and once school started I went and got it cut short. And then I had fun for a number of years growing it out and cutting it, and having all these different styles and things like that until I was 21.

Whereas Gabriella’s hair was once merely hair, after losing it and having it regrow it now took on special significance. She relished the renewed freedom to experience her hair however she wanted.

Gabriella lost that freedom again in the context of a somewhat new and somewhat uncertain relationship.

> I was going into my junior year of college, third year, and I had a boyfriend. I had recently moved in with him, and it was decided that I should probably get some birth control. So I went to the doctor and he prescribed me birth control pills. I was probably in about a month and I noticed I wasn't having to shave my legs anymore. Again, it was summer, so of course I was very conscious of hair on my legs and my armpits. I just noticed that, "Hey, I haven't really shaved in a while. Why haven't I needed to?" And that kind of threw the red flag for me, and the only thing I could think of was the birth control. I'm reading through the fine print and it says, "May cause hair loss." I thought, "Um, that's weird." I called my doctor and I said, "This isn't good. I have alopecia. It started my hair loss again. I stopped today. I'm done." And he's like, "That shouldn't be happening. Why don't we switch you to a different brand?" So I'm like, "Alright. But I'm going off of them for like a month. I want to make sure my hair's coming back in." And he's like, "That's fine." So I quit taking them and my hair seemed to stop falling out. So I started up the birth control again a month or two later, and it was the same thing where I wasn't shaving as much. And so I instantly stopped. And, I would go, "Oh my God, that's it. I'm not going to take them again!" But I ended up losing all my hair. It was just really bizarre because it kind of went from my legs first, but like my left one then my right one, which one was first I don't even remember. All the way, all the way up my body honestly and into my armpits, right side then left. My eyelashes, right side then left side. Then my eyebrows in the same way. And finally, like, 6 months later, it was holiday break for school, and the hair on my head that I had been holding on to started to go. And by the time I got back from winter break I had no hair on my entire body. I think I had a couple strands on my head, but that was it.
>
> When it got to the hair on my head it was in the shower, and you're pulling it out by the clumpfulls. It's like, "Yeah, this is it." And just the same kind of devastation, and "Why me?" I think really similar to the first time around definitely. I knew what to feel. Lots of crying again. Gosh, I don't know. Definitely worried. I definitely was having a boyfriend that we hadn't known each other a long time, although I told him it was a possibility. I would just worry what he thinks. Worrying about how that would affect him and our relationship and things like that for sure. The worry that I won't be accepted by him and that he would have second thoughts about our relationship and me, because I'm not so perfect. I mean no one is, but now this. Mostly I think the biggest worry is to be accepted.

Gabriella's description of her hair loss reveals she had a careful awareness of her body hair. Her rapid response and assertions that she would never again use the medication that started the loss show how important it was for her to lose her hair. During this process, the same feelings returned as when Gabriella lost her hair in her youth, with the added concern about how her partner might react. Gabriella's concern about being accepted shows that for her there was some sense that the AA made her vulnerable in her relationship.

Gabriella revealed that another reason for feeling devastated about the hair loss was that she no longer met her perceived expectations of who she should be.

> I always say I had this stigma of what a college student should be, and she had long hair. And perceptions, like I should be someone with hair at this point in my life and every point of your life. Yeah, definitely.
>
> Like I said, I had this perception of what a college student should look like, things like that. But again, I had hats. Or at least a hat. We had the discussion, "Well is this the time to get a wig?" And I was like, "Well, I would still like to wait and see how long this is going to go," and things like that. I came back from break, and I was there the first week. New semester, new classes. I can sit in the back of the class. I can wear a hat and kind of hide behind it a little bit. And so that's pretty much what I did for the first week. But I always liked to sit at the front of the class. I wanted to be the person with this nice long hair. And after that first week back, I told my mom, "Let's go look at wigs. I think I'd feel more comfortable at school that way."

While her AA was covered by a hat, Gabriella's discomfort persisted because she was not meeting her ideals. Getting a wig might offer a solution.

Gabriella described feeling lost in her experience shopping for a wig, with some negative consequences for not having better guidance.

> It was nice because my boyfriend's cousin, she had alopecia too and wore wigs. That was this world that I wasn't familiar with so she said when she found out a few months earlier, prior, she said "Why don't you let me know and I'll go with you. I can show you the ins and outs and things like

> that." So, my mom and her and I went shopping.
>
> I remember frustration because a lot of wig places are geared towards wearing them for style, more so than disease. I ended up buying one from the second place we went. It was basically like: we went in there, I found one I liked, I tried it on, and I liked it and my mom liked it, and we went up to the cash register, payed for it, and left. Didn't know what to do with it, take care of it, what it was made of, nothing. Because that was just the way it was. I should say some disappointment in that I didn't know what to do either. I thought the experience would be different. And I was disappointed that - I liked what I had but it seemed like I could have liked something else even more. I didn't know if I was in the right wig, and that sort of thing or to cut it to me and things like that. I didn't think to look toward a net of people who are a little bit in the know for that. Internet was there, but we didn't go Google alopecia areata foundation. I think I did at one point, but at the time I went by the yellow pages. In fact, once I did find that good place, it was 6 months later and my other wig was destroyed because I didn't know how to take care of it. Again, I went through the yellow pages and it was the first place I walked in the door to on that shopping trip. And it ended up being fantastic, which was what I needed 6 months prior.
>
> But, at the same time, it gave me back some of my confidence, because I could put that on now and go to school and feel better about all that and not have to worry about what people are thinking or that sort of thing. Definitely a relief. I do remember that. I think just the relief that, no one would really know what's going on. I was just me, that nothing else was happening. I didn't have to hide anything. It was my hair! It's not technically my hair, but it's hair! And it's mine! That was a relief with it, that I could be myself and have the confidence back. I could sit in the front of the classroom. I could enjoy my friends, and not have them wonder what's going on.

With the wig, Gabriella's confidence returned and she felt relief. She could be herself again, comfortably sitting in the front row.

Perhaps remarkably given her concern about what others might think, Gabriella continued to live openly with her AA exposed in certain settings – perhaps places where she did not hold and image of who she was supposed to be.

I worked in the grocery store in the suburban town that I grew up. I liked

> the environment because I could be really open about what was going on, because most people would ask. Most customers, most of my co-workers and things like that would ask, so I could educate them on alopecia and what it was and things like that. But quite a few people would assume cancer: "Do you have cancer?" And I would just say "No, I have alopecia." I hate the question, "How are you feeling?" because it implies that I have cancer, or something like that. So I found a good way to deal with that. I would, at the time I was just wearing hats to work. I would wear my wig during school and stuff like that, but on the weekends and when I was at work I would wear hats. I would just wear my cute little grocery store hat. I was playing softball again, with a news reporter with the local newspaper. So I said, "Hey, will you do a story on me and my alopecia so that way when all these customers and coworkers come in they already know what's going on and they don't have to ask questions?" So I did the story, and he did a nice job with it. It seemed to stop so many questions or weird looks. Everyone was just like, "Oh, she's in the paper. That's cool." I thought it was kind of exciting because I could really educate a lot of people all at once. Again, probably a little bit of relief that, "Okay, now all these people know, I don't have to hide it. And they know specifically what it is, they're not going to ask me if I cancer or how I'm feeling." That sort of thing.

Gabriella acted to increase her comfortability, so she would not have to be concerned about people knowing. She appeared to be more concerned that people will misinterpret her appearance as a symptom of some other condition. Having understanding for the reason for her hair loss was enough to make her feel comfortable living with it openly.

Gabriella shared that her discomfort when people ask “How are you feeling?” or treat her differently – both in the past and today – is that others might perceive that she has cancer.

> *My* perception is that they're asking me because they think I have cancer. And that they don't fully understand, and then that means that I didn't educate them well enough that they know nothing's wrong with me – I just don't have any hair. Sometimes that gets looked past because I had someone ask me that once and I said, "I don't have cancer, I feel fine." And she said, "Oh, I know. I knew you had alopecia." And I'm like, "Okay, don't ask me how I'm feeling!” I don't know, it bothers me! It's rare when someone asks that. No one really asks me that anymore. It's just like

> once maybe twice that someone's asked that.
>
> I had a coffee shop experience. This was several years later. I actually had my wig on and if you wear wigs you can sometimes tell other people that wear wigs, that sort of thing. You can kind of tell around the hairline. I was in this tea shop with my best friend and we each had our daughters with us, so this wasn't that long ago, 4-5 years ago. We both went through the line and ordered our tea, and then you go sit down and they call your name to go up and get the tea. And the lady behind me all the sudden came over with my tea for me and my daughter. And, I'm like, "Okay." And she goes, "Oh, my gosh, I noticed you are wearing a wig. Do you have cancer?" And I said, "No, I have alopecia. I just don't have any hair." And she said, "Oh, okay." And she just kind of like walks away. And it's kind of like that feeling of, "Okay, now what? I don't have cancer so you don't care about me?" That's kind of the feeling. To be singled out. Why are you bringing me my tea? I'm just out enjoying my day. Just because I don't have any hair doesn't mean I need anything special. But, I guess she thought I had cancer so she thought I would like be tired and not be able to go get my tea. I don't know, I have no idea.

The meaning of these experiences is difficult for Gabriella to identify. She seems to feel frustrated about being misunderstood and treated differently. Perhaps it is frustrating to try to minimize getting special attention, but to get it anyway.

Gabriella described the day-to-day impacts of AA on her life at 21, when the hair loss worsened, by noting that it affected her life differently based on the space or social setting she occupied – and whether she expected to feel “completely normal” or concerned about how others might react.

> It probably depends upon the day and what was happening. Like I said, I think at school I probably had a lot less confidence. Don't ask me why I wanted to keep it a big secret from school. I think it was tiresome trying to explain it to other people. And I don't care for perception – like people judging and going to the automatic, "Oh, she has cancer." School was probably tougher because I was trying to hide it. But then, during work and at home and family, I can be completely normal, not worrying about it. No one even really said anything about it. It was life as usual. So was school, but in a different way. I have a lot of close friends, and again it's from music and band and being really involved in that. It was like the

> same reaction as the first time around, they almost knew. But, I was able to go through that time with my best friend who was there the first time around. I think she probably tipped some people off. We had a music lounge and we would always hang out, all 20 of us that were always together. I don't know if people were asking her what was going on, but no one really ever asked me in that close-knit group of friends. I don’t know if I don't like people worrying about me, or if I just didn't want them to know. Why? I don't even know that today. I don't know, I can't tell you.

Again, the meaning of the discomfort about talking about the AA is difficult for Gabriella to identify. She described being confronted by others’ reactions to her AA at school as somewhat fatiguing. Gabriella seemed to merely want her life to go on as usual, and perhaps expected that talking about it might somehow change things.

Gabriella described feeling relieved in relationships in which she was treated as though nothing had changed. She explained regarding her close friends’ reactions:

> It was a life savior. Because, like I said, they didn't really care. They knew so they didn't have to ask. I didn't have to explain anything. They knew what it was. At least my close friends were like, "Oh, it's just another day."

While she appreciated not having to talk with friends about the AA, Gabriella explained that the difficult part of being at school in the presence other students was because they were *not* talking about it.

> I felt like I would have to educate them and explain it over and over. I think the hardest part was away from my friends at school. It's a University, it's not like you're with your friends all the time. You're studying other subjects and things. And just having everyone else in the classroom stare at you or wonder what's going on. No one asked what it was or what was going on, that was either my friends or other classmates, but students that I wasn't friends with no one ever asked.
>
> I like when people ask because it's my chance to educate them and tell them that I'm not sick, because otherwise I'm sitting there thinking that they're thinking that I have cancer. And I don't know why, I mean, why cancer? I guess just because it's considered so much worse than just not having hair. Because you're physically ill, and I'm not physically ill.

> Maybe I felt like they thought I would be weaker because of that? I don't know. It's unfortunate when people don't ask, but at the same time I think it's a good thing because they're not looking at me differently because they must know somehow. I can say that today.

Gabriella's discomfort with her AA at college was that other people would assume that she is sick. The discomfort was not there with her friends because, even though they never talked about it, they knew it was not cancer.

In contrast to feeling lost and alone in the first wig shop, Gabriella experienced a second shopping experience in which she found someone who knew about AA and took the time to educate her. She left feeling confident and well-informed.

> I walked into this hair salon that had wigs. I went up to the reception desk, and they're like, "Can we help you?" And I said, "I'm looking for a wig." And she's like, "Well do you have an appointment?" I said, "Well, no, don't you just come in and pick them up and try them out?" And she's like, "Oh, you have to have an appointment here." And I'm like, "Oh, okay." And she's like, "Oh, hold on, I'll go see if someone's available." So she went back there, and sure enough my stylist was available, and she was my life savior so many years later. She's like, "I have time, come on back." And, so I went back and went through the whole thing, "What are you looking for? Do you have alopecia? You don't know, maybe it'll be back tomorrow, maybe back two years. How long have you not had hair? Maybe you can base it off of that. Because, if you've only been missing it a little while, maybe it will come back soon." She used that to base off what sort of products she would try on me and that sort of thing. We went through everything. I knew when I walked out the door I looked like a million bucks, and I knew how to take care of what I just got too. It was a million-dollar experience. From there having that place and that outlet, I wore my wig all the time. I wouldn't say all the time, because I don't sleep with it, but every day all day. And then I started wearing it to work and things like that. And it was just funny because people who hadn't seen me in a little while were like, "Oh, my gosh, did your hair grow back?" I said, "No, not that fast. No." So that's funny.

Even though Gabriella previously felt comfortable in a number of settings without her wig, the wig now became a something she chose to wear consistently. She felt great.

Gabriella also described her experience going to a dermatologist and trying treatments at 21, and that she took an approach of not wanting to do anything that would impact her health.

> I had punch biopsies and stuff done to confirm the diagnosis. I had blood work to rule out other things. For me, I wouldn't do any sort of treatment that would cause any reactions. I don't want something that's going to make me sick when I'm not sick just to get my hair back. It's not a big deal to me in that regard. I'd rather feel better.
>
> A dermatologist suggested doing Rogaine with minoxidil or like a topic steroid. And that was kind of fun too [Sarcasm]. Because the Rogaine I had to put on at night and then I couldn't wear anything over my head. I had to be totally bald for a couple hours so that it would dry. Otherwise you rub it all around your pillow, and then it will rub all over your face. You could start growing facial hair. I'm like, "Oh, brother!" So, anyway, I'm like, "Alright, I'll do this and then the topical in the morning." At the time I had a wig, but if I went out in public I'd wear hats. I was bowling at the time because I'm a big bowler, and I was bowling with all the men and men's leagues. I can remember, I would have to go there without like my hair on. I'm like, "Oh, man!" Because like I have to go there and do this, or I can't bowl - which isn't an option for me. So I'd end up going in there without my wig. I can't even tell you any specific stories. Obviously the guys that I knew really well, the word of what it is spread through there pretty fast.
>
> It was for several months, at least a few months. My hair kind of did try to grow back. It's such a pain in the butt treatment. I didn't want to go without something on my head because it was the dead of winter. It was cold out, so you don't want to go without something on the head. And my dad tried Rogaine one time too. He just had male pattern baldness. He's like, "It's harder to grow back and as soon as you stop taking it, it stops and falls right back out." And I had the same experience. It was like, "Oh, there's some peach fuzz coming back, I'll just stop because this is annoying." I stopped and it didn't conjure anything. It just fell right back out. It was kind of funny. I didn't really care if it was peach fuzz, and I didn't have a whole lot of hope anyway.

That Gabriella considered it more important for her to go bowling with her bald head exposed than to stay home shows that if there was any concern about what others might say or think, that doing the things she loved was more important. Gabriella continued to live her life in other ways as well; over time she dates, gets married, and has a daughter.

> I think I was fortunate with the last couple of guys that I dated when I didn't have hair. I met my significant other through mutual friends. They had known about the condition and were able to tell the other person before we even dated. So, I think it was pretty funny when I met my husband. We had gone out on our first date, and I kind of wanted to be open about it just to let him know right away, just because I'd rather tell people right away, especially people I really want to have a deep relationship with. But, I told him because I didn't know that he knew. He was like, "Yeah, I knew that. No big deal." I was like, "Oh. Okay. That works for me." Now I have a 7-year old daughter and it's a regular part of her life. She doesn't know me any other way. So, if she asks me any questions I just answer them. Pretty simple.

In various social situations throughout Gabriella’s adulthood, she was faced with the choice of disclosing the AA or wearing the wig. She explained her approach to dating was to disclose early on, which seemed to go well.

In most other settings, Gabriella has chosen not to disclose about her AA. However, more recently she has started to want to go without her wig, and feels concerned about how to make the transition.

> Once I started wearing the wig, I probably hid under it a lot. I wore it all the time up until last summer, and that's when we started going camping and I wouldn't wear it on the weekends. But I'm in this house almost 3 years and none of my neighbors know. I've been at my job 9 months, none of my co-workers know. Some of my co-workers at the last place didn't know, and I had been there for 4 years. I can hide, but at the same time after not wearing it on the weekends I kind of don't want to wear it all the time. But I don't know how to approach it now. I'm not just going to show up without my wig on to work. So I feel like I have to tell them. But how do you bring it up in everyday conversation?
>
> Alopecia has not come up looking for jobs, other than the last job I got about a year ago. I kind of wanted to tell them right away because it was like, "I'm starting over. I can tell them right away and be done." And I thought, “I'm going to interview with my wig,” because I've heard that you

> should so that they don't automatically worry about you having a medical condition and you not being able to perform your job, and so on and so forth. I was like, "Okay, I'll wear my wig." Well, yeah, I've worn it every day since. I just don't know how to bring it up. I have definitely thought about it.
>
> We have our camper at a camper park up north. I don't wear my hair up there, and the resort owner asked me, "Oh, what do you have." And then I explained to him what it was, and then, "Oh, okay. No big deal." And he's like, "I won't tell anyone." And I'm like, "You can tell anyone and everyone you want." I'd rather have people know what it is than to assume other things. So, a couple of my friends up there know and have asked and we've talked about it, but other than that no one else really asks. I'm guessing word kind of spread. Having my husband, he has a lot of friends up there and he's really open about it too, and explaining what it is. I think they ask him a lot instead of me. I guess it was just pretty easy because it was a new thing for us. I was able to just kind of make the conscious effort. I don't really want to wear my wig when I'm up there. It's uncomfortable and it's hot and I'm outside a lot. And, it's annoying. So, I just went there without it. And if people asked I just told them. And that was just kind of the way it was. It felt good to just kind of be accepted for who I am and not have to worry about really what anyone thought. I think it was a new opportunity for me to not have to wear a wig. It was all new, new people to me. It wasn't anyone existing that I had to reveal this years old secret that I had, or anything like that. It was just, this is just who I am and this is what it is, and that's it. I didn't shock anyone.

Gabriella seems to find it easier to be open with her AA from the start, than to reveal to people that she had kept her AA hidden. She has difficulty finding the words to describe why she now prefers to go without the wig, but perhaps there is a greater authenticity to who she is.

> I'd have to say I do feel different when I don't have my wig on versus when I do. In everyday life where everyone knows everything about it, I feel so much more comfortable and so much more *me*. I can't even explain why I feel that way. I can't even say the feelings that come with it or anything like that. I just feel more comfortable with it off; I think I just feel more comfortable not having it on all the time. I don't know why. It's not like I act differently. I don't know.

When thinking about the meaning of Gabriella’s AA, and how she wants to be in the future, she acknowledged that the process has involved emotional ups and downs – perhaps more than she had previously been aware of before taking part in this interview.

> I guess the biggest thing I've taken away is just that it probably consumes more of my emotions than I maybe first had thought, or that I had thought prior to our first interview. And not in a bad or even a good way, just that I didn't realize it affected me that much. Because I feel I, I just put on my wig every day and just walk around. And I'm quote un-quote "normal." I just had never like really thought about all the feelings from all the different experiences. And that it was a whole process with all sorts of different emotions that I had never really thought of before.
>
> For the future, probably back to the emotions part just being more aware, like maybe being more aware of my alopecia and how it does affect my emotions and other things. More than just life in general I guess. Yeah, being more aware of what that is. And what it means.

Gabriella feels she is at a point in her life now where she chooses to fully integrate all aspects of her experience, emotional and otherwise.

The Typical Day

Summary. Gabriella's typical day largely goes by without noticing or experiencing her AA, until the evening while in the comfort of her home. She is at that time faced with the dilemma of wearing the wig when she might be seen by neighbors, despite perhaps preferring to go without the wig.

Detailed description. Gabriella explained her AA at present tends to be a passed through experience – one in which she unconsciously goes through her routine rarely being pulled out by sensations or psychological experiences.

> I guess for me everything is pretty automatic at this point. I just wake up. I don't really give too much thought to any of it. I'm able to just throw my wig on, brush it out a little bit, and out the door I go. Not much in the way of any of that. I don't really give any thought to any of it all day because I wear a wig, so no one knows. I just go along about my life. I honestly can say I don't really think of it at all. In the evenings, like after work and whatnot, usually I just want to pull my wig off. In a typical day I usually

> just keep it really close. I want to pull it off and if I do, I usually keep it really close in case the doorbell rings or I have to take the dog outside. Those sort of things. So I guess I think of it in that point usually mostly in the evenings, I think of the idea of having alopecia. But it's pretty automatic, I don't really dwell on it. And then I'm just relieved to take it off at night and set it on the wig stand for the morning.

Gabriella explained the exception to her being relatively unaware of her AA is in the evening, when she is mindful of putting the wig back on for situations in which she might be seen by others expecting her to have hair. She explained:

> Just because my neighbors don't know. So if I have to go to the door or something I don't want anyone to know that I don't have hair. Otherwise, same thing with taking the dog out. I want to make sure I have it on. I just don't know how to bring it up as an everyday subject. And I'd rather warn people before walking out the door that way. I haven't surprised anyone. If it was brought up in regular conversation, I'd mention something.

Gabriella seemed comfortable with other people knowing about her AA at this point. She had learned from experience that once people know they do not really care, and it does not change their perceptions of her or the way she is treated. For her the biggest issue and the reason she keeps it hidden in any situation is that she suspects the moment of revelation will be uncomfortable, particularly if she has already kept it hidden from someone when they first met. This is maybe why she liked to reveal early to people she considered dating. In her experience, the best case seems to be when she can be open, and other people can help explain and field questions.

Participant 4

The Life Story

Summary. Rachel starts her experience with AA as an athletic teen with a strong sense of self-worth. Those feelings persist throughout her experience with AA. Over the

8 years from her initial diagnosis, her life is gradually more and more affected by efforts to conceal the AA and feelings of distress as her hair slowly sheds. Throughout these 8 years Rachel also is alone in her AA, unaware there are other people with AA. She thinks of herself as an unusual case, which further increases her distress. At a pivotal juncture, Rachel is having panic attacks and decides that her approach to managing her AA is not working. She chooses to change her tactic – shaving her head and getting a wig. Rachel likens this experience to a snake shedding its skin, releasing her from shame and anxiety. She finds a supportive mentor who also has AA and helps her navigate additional hair loss, and reclaims the freedom she experienced prior to AA. Rachel explains the meaning of her experience of AA is knowing she can overcome adversity, which she did when she released the shame and aloneness and chose to live with AA on her terms. Rachel wants to help others with AA so they do not have to feel alone, and to pay forward the mentorship she received.

Detailed description. Prior to Rachel's AA, she had an accident involving her eyebrow.

> I must have been 13 or 14. I was at an 8th grade graduation party. It was a big pool party. I was underwater, and someone presumably accidentally hit me in my eyebrow with either their elbow or their ankle or something very hard. My eyebrow split open, and I ended up in the emergency room. I had 19 stitches, 13 of them internal because it was a very, very deep cut. A big black eye. It was a pretty traumatic experience.

When Rachel's AA presented, first as missing patches in the injured eyebrow, she felt more concerned about the impact of the injury than the hair loss. Even learning about AA seemed non-threatening at that point.

> About 2 weeks after the pool accident happened, as I was still recovering,

> I noticed little small patches, like quarter-sized patches of hair coming off my head. I had these small bald patches. And it was sort of weird, and my mom and I didn't know what it was so we went to our doctor who said, “It looks like you have developed alopecia from this very traumatic pool accident you had. That's not uncommon, sometimes alopecia is caused by an emotional or physical traumatic event. And we don't really know what causes it, we don't know how to fix it, but there you have it.” So that's the beginning. We were concerned that I had side effects from my pool accident. There was some concern if I was going to have sinus issues or if I had a broken sinus. I think it was just concern about what were the side effects from this pool accident. I honestly think the bigger issue at that point was I was still recovering from the pool accident, I think it was less about the alopecia and more about what are kind of the long-term effects going to be if any.
>
> It was a while ago and I was pretty young, so it's kind of hard to remember. But definitely it was a surprise. I had never heard of alopecia. I don't remember being overly concerned. It was sort of like, "Oh well, I can live with this." They said, "It could go away, it's a lot of times temporary." So I wouldn't say I was that concerned when it initially happened.

Once Rachel’s hair loss began to increase, she took notice of the changes in her hair, but otherwise continued to live life as usual.

> By the time I had started high school, or shortly thereafter – so within a few months – it had gotten a little bit worse and I was having more hair loss. It still wasn’t significant, it was still pretty small. I don't remember at that point, I don't think I went to the doctor at that point. I think it was sort of like, “Let's just see how this plays out.” I don't remember being frantic about it. Definitely not a sense of super fear or concern yet.
>
> I think I felt okay about it because it wasn't getting progressively worse. It was sort of like, "I can live with this." And I was really involved, I played a ton of sports in high school, I was super active, and so I never remember it being a focal point of my high school years. It never impacted what I felt like I could do or couldn't do. I told like my teammates about it so that they could help me braid my hair. We would always braid our hair in French braids before games. I played basketball, and cross-country, and tennis for a while. And I ran track. And, I definitely told all of my teammates about it. They were aware, I never hid it. And they would help me braid my hair so that whatever - I had a few kind of trouble patches on the sides of my head and a little bit on the bottom of my head, but nothing that was super noticeable or couldn't be covered by a French braid.
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> I don't ever remember being super awkward. I think it was just very matter

> of fact, like, "Hey, I'm losing these spots of hair on my head. Can you guys help me cover them?" I don't ever remember people being weirded-out by it. It was all very normal. I don't ever remember me feeling like I couldn't do things, or I couldn't tell people. It was just sort of normal.

Rachel did not keep her AA private from teammates, and felt no shame when enlisting their help to cover her patches. These allies confirmed the normalcy of Rachel’s AA in their casual reactions.

Once Rachel started college, the hair loss further increased, shifting from mere awareness of AA to acknowledging its continued presence in her daily life.

> I think maybe the reason it wasn't a big deal for me in high school is because I was sort of in denial about it. Not in a bad way. I acknowledged it, but I was sort of like, this is a temporary thing. It's going to go away. I never thought I had to deal with it. I just sort of ignored it. I just went on with my life, and it just was. I hadn't lost enough hair at that point where I really had to deal with it. Then as I lost more and more hair and I had to go to the dermatologist all the time, then it was like, okay, now I can't ignore this. Now it's actually a part of my everyday life.

As Rachel’s symptoms increased she began to experiment with treatment options.

> When I was in college I found a dermatologist. I would go in once every 4 or 6 weeks, and he would inject cortisone shots into my bald spots, because they had gotten bigger at that point. He was doing the best he could, I don't fault him for it, but he had never really treated anyone with alopecia. He was a really young guy himself, this was a whole new experience for him. I feel like I was sort of a guinea pig. No one really knew what to do with me. The dermatologist was very friendly. I never felt bad, I always felt like I was in good care. But cortisone shots, maybe they staved it off a little bit longer, but they certainly didn't help my hair grow back. No hair was growing back. I would still go to him, and he would give me cortisone injections just on small portions of my spots. He wouldn't do all my spots, but maybe the most noticeable ones he would do. The spots were getting so big that my dermatologist was like, "These cortisone shots aren't going to do the trick anymore. Your patches are too big." He definitely got to the point where he was like, "I don't know what else to do. But maybe try this prednisone." And so for a while, maybe up to a year, I was on oral prednisone. I think it was sort of just the attitude, “What can I lose?” Let's just try everything. Like throw at me whatever

> you have. It didn't help anything at all. My hair never grew back with that. And maybe it staved it off longer, but it didn't really help. I think maybe I got a little bit bloated. I don't remember having any really bad side effects. But when I went off the prednisone is when it just went to hell. Basically all my hair just started falling out after I went off the prednisone. To this day I sort of blame the prednisone, because I know it's a really strong drug. I think it wacked out my body. After I stopped taking the prednisone, my hair loss got progressively worse.
>
> I got to the point when I was in college – I must have been like a sophomore, so it must have like 2006 or 7 – I was like, "Okay, well this dermatologist isn't helping and Western medicine isn't helping. Let's try something else." So I found a reiki therapist through a referral from a friend. And reiki is an ancient art of energy healing, I think from Japan. It certainly didn't help my hair grow back. I would go probably once a month and see her, and it was a combined massage-reiki appointment. My hair didn’t grow back, but I think it helped me kind of cope mentally with the hair loss. So I guess it did help in that sense. My therapist talked a lot during; it wasn't a silent session. She would talk about how your energy can basically – if you have positive energy you can bring positive things in. I don't know if I believe all that, and I don't know if I believed all of it back then, but I was sort of like, maybe something will work? I don't have anything to lose. I did that for a few years.
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> Then not only did I go to a reiki therapist, I went to some other energy healer. She was a little bit wacky. I went to her a few times. And she was like, "Oh, your hair loss is caused by the trauma on your eyebrow and your eyebrow has never healed from the trauma. There's bad energy there." So I bought some sort of expensive rubbing oil from her, like scented rubbing oil, and she's like, "Rub this on your eyebrow and it will help get your energy in balance." I never felt taken advantage of by my reiki therapist, but like this lady was a little nutty. It was the same thing though. I was sort of like, "Well it can't hurt. Right? As long as I'm not spending a ton of money." Which is why I only went to her a few times because I was like, “Okay, she's sort of wacky, and she's kind of expensive, and I don't think this is helping.”

When traditional treatment methods failed to provide either results or answers, Rachel turned to alternative medicine. While these methods did not prove any more effective at decreasing the symptoms of AA, they provided some help coping with the mental challenges her symptoms imposed.

Despite all the things she was doing to treat her AA, Rachel explains her AA largely did not stop her from being involved in college activities or decrease her self-worth – even in the potentially sensitive realm of dating.

> I was pretty active in college. I started running half marathons and marathons, and I had a good group of friends. I was really involved in the college democrats. I think just going about my daily business and being able to feel like the alopecia wasn't affecting me in any way was a good day. I think most of my days were good days. I certainly don't look back and think of that time as a dark period or anything. It was harder than high school, but it doesn't have a shadow over it or anything.
> Dating was never a problem. I would always tell, even when I was in the process of losing my hair when I was in college, I would always tell the people I was dating about it. I don't think I ever really hid it from the people I was close to or getting close to. I didn't announce it to in a lecture hall or anything. But, all of my friends new, and guy friends knew, and my dates knew. I never felt like I was judged or it was an issue. I feel pretty lucky that I've never had a bad experience with anyone saying anything nasty. I never felt like it prevented me from dating. Even when I was at my worst, even when I felt like I only had 50% of my hair, I still had pretty good self-confidence about myself.

Rachel told others in her life and never felt “judged.” She mostly maintained involvement in activities, and did not withdraw from close relationships. On rare days, the AA was more distressing.

> The worse days were when I would get out of class and I would be kind of paranoid about one of my spots. Like, "Oh, my gosh, I think one of my spots is showing. I think I felt a shift." Then I would run to the bathroom, and I would check in the mirror. I would re-adjust my bobby pins. I think those were the bad days; having a little bit of paranoia about “Are my spots showing? Is it really obvious?” I think those were the more stressful days.
>
> I would just be like, this is going to look so weird to people. I'm going to get stares. People are going to think I'm sick. Or, it was embarrassing. I generally have really good self-esteem. I thought I was an attractive person, and I never had any body image issues. But this was just so undesirable to anyone, not to just men, but to anyone. They would be like, "Oh what's wrong with her? Like, what?" Just like, "Ugh. What's going

> on?" I don't remember having those thoughts all the time. I'd say those were a bad day thought.

The intensity and prominence of the AA varied. On a “bad day,” Rachel revealed there was shame and concern about judgement should her AA become the focus of others' attention. This was despite her generally having a positive body image and a history of close friends responding contrary to her concern.

As her hair loss continued to increase, Rachel's life became increasingly impacted by her AA.

> I had a specific pattern of alopecia where it was in the nape of my neck like in the back, which was actually a good spot to have it because you could hide it. Your hair kind of covers it up. And then I had a spot on I think it was the right side of my head, and the spots would just sort of grow bigger. And at that point, it got to the point where I could tell when my hair was going to fall out, it would tingle. There's kind of a burning sensation, like someone has your hair in a ponytail and they're just like ripping it out of your head. And so that was stressful because I'd get these tingling sensations that were kind of painful and I'd be like, "Oh my God, crap! I'm going to lose more hair!" I know what that means. That was stressful. I think it's a sort of like, I didn't have the ability to control it. I knew it was going to happen and I couldn't do anything about it. It was like, "Oh God, I'm doing all these things, I'm getting cortisone injections, and why isn't anything working? Why can't I stop this?"
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> I think some days were better than others. There were definitely times when I would feel stressed out about my hair situation. If I was going out with friends and I had to hide it, then that was sort of, "Oh, why do I have this? Why do I have to deal with this?" Then I think there were other times when it wasn't as big of a deal, and it didn't bother me as much. I think when my head would tingle, which happened more and more the more time when on, that was stressful to me mentally. It was like physically stressful, and then I couldn't escape the knowledge that more hair was going to come out. I could be doing whatever and not thinking about it, but my head hurt. And then I couldn't escape knowing that there's more to come.
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> Showering was really stressful for me during that time, which is so weird. I love taking showers now. I cherish them. Before I go to bed I take a

> shower now, and I love it. But, back then I remember – this is sort of gross and weird – but I think I would not shower sometimes. I think I'd go a few days without showering, because the thought of going in the shower and washing my head, and having hair in my hands when I got out, or coming out and seeing hair on the bottom of the shower, I just was like, "I can't, like I can't deal with that." It's too much. I kind of forgot about that, but showering was a super stress-inducing activity.
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> As I went through college it got more and more to the point where I was having to put bobby pins in a certain way and wear my ponytail a certain way. Like there was less flexibility the worse it got about how I could wear my hair. But through the majority of college, it was bad but it wasn't so bad that I couldn't figure out a way to hide it.

Rachel seems to describe a feeling of helplessness. Feeling physical sensations or seeing visual reminders of increased shedding was particularly distressing, and pulled her out of her everyday experiences. Rachel had to wear her hair certain ways to disguise the hair loss, but she still considered her AA relatively manageable.

Another aspect of AA for Rachel in college, and one that is still painful to think about today, is feeling lost and alone through this process.

> I think for all through high school and most of college, there wasn't a sense that other people had this. So I think it was like – sorry it's kind of hard. I think just, thinking that I was alone and that no one else had this, like I was the only person in the world who had alopecia was really hard. And then, my dermatologist never, like I look back now and I think, why didn't the dermatologist offer to… there must have been alopecia support groups or some sort of resources. And I never knew about them. I felt, definitely, felt alone. I don't talk about that part a lot because it's done and over like I can't help it now. But I look back now and I'm like I wish, I wish someone would have told me. Or maybe me, maybe it's on me, like maybe I shouldn't blame my dermatologist. But I think I was sort of still a kid back then, and I wish an adult had been like, "Hey, there are other people who have this."
>
> And then I discovered, online support groups, and that was really helpful. It must have been 2007, I had already had alopecia for like 5 or 6 years at that point. And basically, had thought the entire time I was this really strange case. Like they had never seen anyone else with it. It was kind of

> before the age of the internet, so I had never done any research. It was just sort of this bubble that I was living in by myself. I think that once I found the support groups, alopecia world was really helpful for me when I first discovered it. To be like, "Oh, there are people way worse off than I am." Or, you know, to see how people are dealing with it. And I was like, "Oh wow, there's people all over the world that have this." So I just found those really helpful, to be like, "Oh, there are other people, like all over the world that have this." And, like, "This is how they're handling it." And like, just to basically know that I wasn't the only person, I think just that in itself was just really helpful.

While her dermatologist attempted to treat the physical symptoms of AA, her emotional needs remained unattended to. She felt alone with her AA. When she eventually discovered a community of people who shared her experience, she began to find some solace.

Eventually the AA spread and the presence of bad days increases; Rachel became overwhelmed with distress and limited in the things she can do.

> I think it was my final semester, my spring semester when I was a senior. So it was the spring of 2009. And, it got really stressful. Then it became more bad days than good days. I was really, really stressed out about my hair. It was so hard to wear it at all at that point because so much was lost. There was no way I ever could have gone swimming. I couldn't go out on a windy day. All these restrictions started coming into my life. I'm really active, and I never had that many restrictions on my life. So it felt really, really devastating, feeling like I had to live in this bubble where I couldn't be near water, near wind, or I couldn't get caught in the rain – otherwise my spots would all show.
>
> I definitely started having panic attacks. I would be in the car, I would be driving to or from campus, or I was working - I worked all through college - I'd be going to my job or whatever. And, I remember a few times having to pull over onto the side of the freeway and just being like, "Oh my God, I can't breathe." Just feeling panicked, and then realizing, "Oh my God, this is a panic attack." So then my quality of life went down because I was feeling so panicked. I was like, "What am I going to do medically about this? Nothing is working." And I think in some ways I was still sort of in denial. Some part of me was still like, “This is going to get better now.” I should have known; it's not going to get better. But I think a part of me

> still held out hope that it'll grow back some day, even though it had only been getting worse for how many years at this point. So then I ended up having to go on anxiety medication because I was so anxious all the time. Which was hard, which was definitely hard. I had to make a decision: Do I keep living like this? Can I just live perpetually in this stressed out state of constant panic attacks? Or do I move on? Deciding to move on was hard because I think I felt in many ways like I was giving up. I had been fighting for so long. And I just thought: I could run marathons, why couldn't I fix my hair? I think there was definitely a mental adjustment that had to happen. The point when I started having really bad panic attacks was the point that kind of I think did it for me. I could live forever like that, but it would be miserable. I have to find another solution, because this isn't working. I think I moved out of the denial phase, which I was in various states of. Maybe not denial, but just wanting to fight it. Having to give up the fight was really hard.
>
> Then I started researching wigs, and what my options would be, which was really hard because to me it was never an option. I never once even thought about getting a wig. That was never even option Z. It wasn’t an option. So getting to the point where I was looking that up was the first step in changing how I felt about the situation, and knowing that I had to make a change.

Rachel faced the pivotal decision of whether she would continue to live with constraints, or find an alternative option so she can once again live her life on her terms. She chose to stop fighting – to stop trying to regrow her hair. She then started looking for a new way of managing her AA, and considered options she had never thought would be possibilities.

Rachel also found support and community in this process, support that she had been missing up until this point for 8 years of having AA.

> The support group online was how I figured out the different kinds of wigs, and the different kinds of hair you can get on wigs, and how much they cost. And that was how I gauged where to begin. It was a whole new world. I didn't know anything about wigs. Then I found what appeared to be the best of the best wigs, which are the wigs I have now. I contacted the woman in Chicago who was the representative for that region. I contacted her and she drove up to my house, to my parent’s house, which was a solid

> 2 hours north from where she was. That was very kind of her. She also has alopecia. So that actually was really helpful. Now that I think about it it's sort of amazing, she was the first person I had met in real life. It took me 8 years to meet someone like me. So I really trusted her, and she has never let me down. She's sort of been like my mentor. She's really well put-together, and she is beautiful and has great makeup and great hair. So it was like, "Oh wow! Like she looks better than people who have real hair!" It felt encouraging. I felt encouraged and hopeful and less alone. And, I was just like, "Well, this person - they figured it out. I can figure it out." And I have her to guide me, she didn't have anyone to guide her. It was really good.

Seeing someone with AA who looked phenomenal provided Rachel with a new representation of who she could be; wearing a wig and having AA did not mean she would need to give anything up.

The day Rachel shaved her head was monumental for her; a day where she reclaimed her life surrounded by the support of her family and new mentor.

> The wig representative shaved my head. She took a measurement of my head for the wig. I think I felt relieved. It was like, this has been a long time coming. You know, even as I was doing it I never thought this was the wrong thing. I never felt like turning back or jolted or anything. It just felt right. It just was a relief. It was a big day. It was a really big day. It was April 23, 2009. I think that was sort of the next chapter. I was ending being the victim and I was starting as a new me. It was over. The fight was done. The crazy thing is that I thought that I would feel like I had lost the race, but I actually felt like I had won it by shaving my head. It was pretty cool. It was pretty cool.
>
> It was a pretty cool day. We sat at my table, it was me and my mom and my grandmother who was with us. And, my grandma, she had 11 kids. And she was a super unemotional woman. Like I had never seen her cry. She was just very pragmatic. When you have 11 kids, I think you don't have time for emotions. And she cried when they shaved my head. And, that was really, it was sort of special, sort of hard and sort of special to see that I meant that much to my grandma that she was that concerned or that proud or whatever her feelings were. I wish I would have asked her before she died, but she cried when they shaved my head. And to her dying day, I never saw her cry other than that. So that was definitely really a memorable moment.

After years of struggling with her AA alone, Rachel could see the support and acceptance from those close to her.

Shaving her head was the catalyst for several changes; she went from distressed and constrained to completely freed.

> And then after my head was shaved, I was like, "Oh my God! Why didn't I do this years ago?" I'm like, "This is so much better!" It was like shedding *all* of this anxiety and all of this denial. I had just shed all of it. Instantly, all of it came off with my hair. Like shedding my snake skin or something. I was just like a new person. I was able to go off my medications. I would walk around town with no wig. I would just walk around with my baldhead. I would go to stores with my mom with my baldhead. We'd run into people we knew with my baldhead. I think I was so sick of being afraid and ashamed, that when I shaved my head I was like, "Well this is it! This is me now!" I'm not hiding it anymore. It was like so liberating. My only regret through my entire process is that I wish I had done it a year or two sooner. I think I held on for a little bit too long. But it was hard, I definitely felt like I was losing a piece of myself. That's how I describe it. Or losing a really good friend. And I think as women we have these really close relationships with our hair, at least I think a lot of women do. I definitely did. I loved my hair until the very end, until I shaved it. And having to let go of that; I definitely went through different stages of grief. Really, I went through denial for a long time. I don't think I was ever really angry, but I felt a sense of loss as I was losing my hair. And shaving it all off felt like the final funeral for that piece of me.
>
> I got my first Freedom Wig [which stays on through suction] in September of 2009. And in-between the period of shaving the head and getting my Freedom Wig, I had like a full lace wig that taped down to my head. Which, basically I had to have until they could make my Freedom Wig, which takes a few months to manufacture. So, I remember being in New York City in December of 2009, so I was just a few months into having my new Freedom Wig. And I remember going out onto the Staten Island Ferry. I was out on a ferry, out on a boat, and it was a super windy day, it was in the winter. And I remember being like, "Oh my God. I don't have to worry about patches on my head. I don't have to worry about my taped wig falling off. I don't have to worry about any of it. I can just be free! I can be me!" And that was a pretty cool thing to think about when it hit me. I was like, "Wow, this is the first time I have really felt in a long time like I can just stand on this boat and the wind can whip through my hair and

> I'm not worried. I'm not worried about anything. I can just live."

Shaving was like a catharsis. There was a meaningful loss with shaving her hair, but the loss of shame and anxiety was freeing. Afterwards, any apprehension about revealing herself was confronted directly – no going back, this was who she was now and others would have to accept that. Her new wigs provided additional freedom from constraint. Rachel revealed her new self to someone she was dating at the time as well.

> I met my now fiancé in 2008. So I still had my real hair, and it was, like 6 months before I shaved it. So he knew me when I was really at my worst with losing my hair, when it was really getting really bad. And he didn't care; it didn't bother him. And when I shaved my head, it didn't bother him. I remember the first time I saw him after I shaved my head he just like sort of felt it, and he's like, "Oh my God, it feels like sandpaper." And it was a little strange, it was like, "Oh, I guess this is the new you." But, it was never like a big issue. I guess it was a side thing. I never felt like it defined who I was, even when I was in the worst of it. I still think I was me.

While there may have been an awkwardness to the initial reaction to a new experience for the both of them, it was another area of Rachel’s life where she was open about her AA. Rachel continues to appreciate her transformation.

> So I shaved the head in 2009, and it's only been positive from then on. I think it was the right decision, and I'm super happy with the decision I made. I think I'm making a really good thing out of what can be really devastating for a lot of people. I think I felt like I had kind of suffered long enough. Like I had been in denial and been sort of ashamed for however many years, 8 years that I was slowly losing my hair, and I just was like, "Been there, done that. And it's not any fun and it's miserable. And, so this is just how it is." And it's only been a positive experience since then. I can honestly say I have not had one bad day since then, about my hair, ever. I never think, like "Oh I wish this didn't happen to me" or "I really miss my old hair."

When Rachel considers the meaning of her overall experience of AA, she considers the meaning of being able to move beyond her difficulties.

> I think it's made me a stronger person. I think I feel like I've dealt with this. It was pretty bad for a while, and I dealt with it. I came out on top. So I think I came out feeling like I can handle stuff. I can get through stuff. I'm a strong person.

She has generalized and internalized her experience of AA to mean she is strong and has the resolve to overcome adversity.

Rachel explains the hair loss continued after shaving her head. It was surprising, but with new support did not have to face it alone.

> After I shaved my head, I'd say within 4 months I lost all my hair. I lost my leg hair, and my eyelashes, everything. Nose hair. And that was jarring. But I think I took it in stride, because I was like, "Well, the worst has happened. I already lost all my head hair, losing my leg hair isn't that bad." Losing my eyebrows and eyelashes was a little bit tough. I had to learn how to do makeup, which I had not really ever worn before. Luckily I had my great mentor, my wig lady in Chicago. So I didn't feel like I had to figure it out myself. I had someone helping. Like I had a community that helped kind of, helped guide me.

Having support meant that she could easily find understanding as well as strategies to manage her appearance. She has even grown to appreciate her new beauty routines.

> I would say the more I lost hair, the more I noticed other people's hair. It's funny how it's flipped, because I used to see someone's long beautiful hair and be a little bit jealous. I'd be like, "Oh God, I wish I had that hair. They don't know how lucky they are." And, now I'll see someone's hair and I'll be like – because now I love my wigs and I think they're like the most beautiful things ever – now I'll see someone's hair and be like, "Oh God, that girl needs to go get her hair deep conditioned." So it's like totally flipped.
>
> I wear fake eyelashes. So that has actually become sort of like – I like to think of it as like my trademark. You will never find me without my fake eyelashes. I put them on every day. I love them. I don't feel like myself without them now. I think even if all my eyelashes grew back I'd still wear them. I think I started using them pretty quickly. I get them just at CVS. They're pretty cheap; I don't get anything fancy. I think part of the reason I started using them right away is because you actually get a lot of gunk in your eyes when you don't have eyelashes. They serve a purpose outside of

> just being aesthetically pleasing. And so I actually think part of the reason I started using them was because I noticed my eyes were just getting full of junk all of the time.

Rachel even started contributing to others going through the same process as her.

> I've definitely tried to help other young women who have it to the extent that I can. I met with a girl in D.C. who is college-aged, who is very uncomfortable in her own skin. She had a Freedom Wig, but it wasn’t cut very well. She didn't really know how to do her makeup. So I brought her a goodie bag with my favorite makeup items and the tricks of the trade, which is basically what my mentor did for me. I'm trying to pass that along. I think it's maybe happened so that I can help other people who have it. And show them that it doesn't have to ruin your life. You can lead a really happy life. I think about the choice I made to carry on my life and not ruin it, and it really could have gone either way. Like I think eventually I would have had to come to that decision, but I say to myself, "I could have been miserable for another two years." Like who knows how long it could have happened. So I hope I can kind of preach the gospel to other people. Like, "Go ahead, shave your head. It's okay, you can let go of it." You can move on from this. It's not the end of the world.

Rachel chooses to give back some of the support she received. She openly shares her perspective, including advice from her emotional experience and practical tips.

Rachel continues to make decisions that maintain her current freedom, rather than entering back into the cycle of trying to regrow her hair.

> That was the end of that story. And even now when I go to the doctors and I tell them I have alopecia, they'll be like, "Well, are you doing anything about it?" Or like, I've had dermatologists be like, "Well, we can try this, we can try this." And I'm like, "Oh don't worry about it." I'm like, "It is what it is. It's not going to grow back. And I've accepted it. And I'm not going to do all these crazy things to my body to try to fix something that just is how it is now."
>
> And, some of my hair has grown back. So I was totally hairless for I'd say about a year and a half to two years. And my leg hair has grown back. A lot of my head hair has grown back, enough that I think that if I grew my hair out now it would be probably at the same level that it was when I shaved my head initially. But it's never enough hair; I couldn't grow a full head of hair and be happy. I could grow my hair. But it would be super

> patchy. My head looks sort of like a globe. And some of my eyelashes have grown back, not all of them.
>
> I got my eyebrows tattooed, I think 4 years ago, because I was sick of my eyebrow makeup basically coming off in sweaty weather. And, the weirdest thing happened. Shortly after I had my eyebrows tattooed, they grew back. And I have beautiful, full eyebrows now. And I still tattoo them because I like them a little bit darker. But I have great eyebrows now, and I sort of think that like the tattooing of them, like the pressure grew them back.
>
> It's been through a lot of phases. I've had alopecia areata, and then just totalis, and then universalis, and now I'm back to totalis or areata. I don't know. I shave my head now twice a week so that I can wear my wig, because they suction onto my head. But I still have to shave my legs, which is sort of annoying. I'm sort of like, "If I'm not going to have my hair, I might as well not have any hair."

Rachel is finding some hair regrowth on various areas of her scalp and body, but maintaining beauty routines including wigs and tattoos – some because of her preference for her look.

Rachel explains some social encounters when she does not have her AA covered that are out of the norm of her typical experience.

> One time when I was running I had a little kid look at me, and then look at her mom, and go, "Mommy, what is it?" And I was like, "Uh, I can't even be mad." Like it's a little kid and they're confused. Because I'm obviously a girl, but I don't have any hair. And I wasn't offended or anything.
>
> Then I think one time I was in the bathroom at my work without my hair on, and as I left the bathroom there was a cop waiting outside. I worked in a building that had like police officers in it. And I think someone had called the police on me thinking I was a man in the women's restroom. But I wasn't upset about it. I think it's sort of funny. I don't know. Most people are really open-minded. It felt actually sort of funny to me at the time. When it hit me I was like, "Oh. Ha-ha! They thought I was a dude!" And I don't mind because, I'm obviously not a dude. Like if you saw me, I'm clearly a girl. So I don't know, it's just funny.

These unusual experiences are interpreted for what they are – something outside of

Rachel’s norm. She does not feel offended or hurt, recognizing the very obvious contradiction between her self-view (“clearly a girl”) and the occasional misperception of others.

When Rachel thinks forward about her future, she continues to think about contributing to the AA community.

> Hopefully I can have a business that helps other people. Or if it's not a business, then somehow be more involved in the community; just be an advocate however I can. Like if I have kids there's a good chance they'll have alopecia, so being able to shepherd other young people through it I think is good. Because I think I did feel really alone for a long time. I definitely don't want other people to feel alone, and hopefully now that everyone has the internet all the time on their phones, I think that there is more of a sense of community. And people tend to feel less alone these days, which I think is wonderful. But even then, I think it's helpful to physically meet people who are like you.
>
> I'm hoping to someday have the time and resources to maybe become like a Freedom Wig seller here in D.C. That's very much a dream of mine, is to have my own business. Because I've found that it really helped me having a mentor who has alopecia. And I felt like I could trust her more than I could trust other people. Like if I had someone without alopecia trying to sell me a wig, I would probably not trust them that much.

She wants to help provide the same support she experienced from her mentor, to help others who may be feeling alone with their AA. She is interested in paying forward the support she received.

The Typical Day

Summary. For Rachel, the typical day at present involves paying little mind to her AA. The AA does come up for her in certain settings, it is usually because she chooses to share about it or wear a hat that reveals her baldhead more so than her wig. In both situations, she explains others’ responses are generally accepting. She contrasts this to her years of fearing others’ reactions.

Detailed description. Rachel explained that in her typical day the AA is an unconscious presence, it is there but does not usually draw her out of her experiences.

> I don't really feel like it impacts my day-to-day life that much anymore. Putting on my wig is like putting on a pair of shoes or something. It's just very normal. I don't ever really think about it, other than like, "Oh, thank god I can come home and take my hair off.” I would say it's not any more a part of my day than eating breakfast. I don't ever think about it. It's so strange. Like, I just think I spent so many years fighting it and now it's just part of who I am. It's not weird; I don't ever feel weird about it.

Differences in social settings – sometimes wearing a different wig or wearing a cap to exercise – present the potential for negative social encounters.

> When I go for a run – I run a lot. I don't run as much as I used to but I try to do a few races a year. And I wear my baseball cap out. I don't ever wear my hair when I exercise. I've belonged to a yoga studio for about a year and I never, ever would fathom wearing my hair to a yoga studio. I just wear my baseball cap. There have been a few times where I have been at the gym, and I've forgotten to bring a baseball cap. And I'll have moments of like, "Do I want to go out without"- because my baseball cap still is a little bit of a safety for me. Like I don't feel as exposed when I have my baseball cap on. But I've never let it stop me. If I forget my baseball cap and I'm at the gym, I just go out without it. Like I'll think about it for a second, and then I'll be like, "Whatever. I don't care." Like it seems to me that I have such a "I don't care about it” attitude that I have never experienced, *ever* a negative reaction. No one has ever stared at me. No one has ever been like, "Oh are you sick?" I've had a few people who have been inquisitive and who have been like, "Hey, like, why have you lost all of your hair?" But I’m totally happy to tell them. I have never felt like it was in a negative way. They're just curious. I'm sure I just delve so far into my story that they're just like "Shut up" by the end of it.
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> Yeah, I don't think about it at all. And the only time I ever think about it is, like today for example I wore one of my shorter wigs. And I had a co-worker be like, "Oh, hey you got a new haircut! I like it." And, depending like if I'm in a talkative mood or not, sometimes I'll be like, "Oh yeah, thanks, it's my new summer cut." But I'd say most of the time, I'll just be like, "Oh, it's a wig, it's not my hair." And they'll be like, "Oh." And then I'm like, "Oh yeah, I have alopecia." And then I'll like tell them the story.

> And, I'd say like 50% of the time they either go, "Oh yeah, I went through a bought of alopecia when I was younger." Or they'll be like, "Oh yeah, I know someone with that." Or, "Oh yeah, I've heard of that." Like, it's never been like a weird conversation. People are always really interested to hear about it, and I think because I treat it now so nonchalantly that other people feel really comfortable; like no one ever is weirded-out by it. Everyone is like, "Oh yeah, okay." Or I'll make jokes. Like if I have a stressful day, I'll be like, "God, I just feel like pulling out all of my hair, if I had any left." People think that's funny.

Rachel has made even talking about her AA a part of her normal routine. Interacting with coworkers or even strangers in a public space goes well, which she attributes to her attitude. She “never” had a negative response, a response she might have feared prior to shaving her scalp and choosing to “carry on” with her life.

Participant 5

The Life Story

Summary. Ashley experiences her AA in the context of having recently started a new school in a small town in a new part of the country, and after already being teased for being different. When she notices the first spot, she reacts with concern for her health. She is rushed to a doctor, and reassured that the shocking image of a person with extensive AA will not happen for her. Within weeks she is separated from her family; too much hair is falling out for her to participate in their evening rituals. Without her full consent they shave her scalp completely bald, marking her as even more different from her peers. She feels unfeminine, and questions her physical attractiveness. Medical treatments leave her with the side effect of permanent weight gain, which exacerbates those concerns as well. Ashley found wigs, and struggled with their quality and the experience that others – from cheerleading boards to employers – cared more about her meeting their appearance standard than being comfortable and herself. Eventually she starts a new life in a big city, and attempts to escape her label as “bald girl” by living all moments around others in her wig. She finds living with her wig all the time is not the experience she was hoping for, and tells others in her welcoming, diverse, and eclectic community. She finds her “new normal,” and feels accepted in some environments: first around friends, then a romantic partner. Work is a setting where she learned lessons early on to not be open about her AA, and so maintains concern about her secret being revealed. She expects to experience additional negative reactions to her AA in the future.

Detailed description. Ashley explains the moment she got AA, she started to worry about potential implications for her health.

> It was the summer before 9th grade that I noticed the definitive spots. My family, we were on vacation, we were at some cabin on some lake and I was in the bathroom. I was just running my hands through my hair and I felt the bald spot and it was something I had never felt before, so I started looking in the mirror. And it was on the back of my head, so it wasn't super easy for me to see. And I just sat there like, "What is this?" Trying to look in the mirror. For some reason in my teenage or pre-teenage mind, I thought I had cancer. Because the only things I knew that made women bald, in particular, was cancer. I run up to my mom and I'm like, “Something's wrong with me!” I sat down on the floor. My mom was on the couch and she took a comb and went through my hair. She found that spot, and it was about the size of a silver dollar. She looked around and there weren't really any other definitive spots, but she did see some receding hairline patterns up on my forehead. I was just hysterically crying because I thought I had cancer and I was dying. She called the doctor and they said, “You need to bring her in, we need to look at it.” And my mom and I left vacation early to take me to the doctor. I was fearful because I thought that I had cancer. I felt this fear for my life, more than, "Is all my hair going to fall out?" Because, there was this mindset of, “Well if I have cancer and my hair falls out, if I get better my hair will come back?” So, I was less concerned about my hair at that point, than about my physical health and what I had perceived was going to be a real threat to me.

The fears were serious; rather than thinking about her appearance, she thought of cancer.

Her mother responded with concern as well, not wasting time before contacting and then visiting a doctor. Ashley reflects on that aspect.

> It's as comforting as I think you can have where it's your mom and you know your mom is going to take care of you no matter what happens. So, mom, when the doctor called and said, bring her in, and my mom was like, "Okay, we're going to leave vacation early." You know, we had only been there for a few days. So, I knew obviously that my mom cared about me enough. I knew she cared about me anyways, but I knew that she cared about me enough to soothe my fears by leaving our vacation early to take me and see what was happening.

Ultimately the initial experiences were focused on health, still living unaware of the potential for AA.

Ashley recalls the experience with the physician was reassuring for her health, but that she now felt somewhat repulsed by the potential of what her condition could be.

> I had a wonderful primary care provider. My provider, she was so warm, so lovely. She came back and she was like, “Okay, I'm going to take a biopsy.” And she took some slides, just like the microscopic slides, and she lightly scraped it against my scalp. I remember thinking, "Oh that feels good, keep doing that." She came back and she said, "Okay, we're going to have to run these for tests to see if there is any sort of fungal infection. It could be ring worm.” I was appalled by the thought of, "Oh my God, a worm inside my head somewhere!"
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> And she came back with this book – she had it bookmarked – and she showed me a picture of a person with alopecia areata. She said, “It could be this." And right next to it was a picture of someone with alopecia totalis or alopecia universalis. And so my mind was like, "What the f--- is that?" And she looks at me and was like, "This is not going to happen to you, we are not going to let this happen to you." I went home, and I think I had this sense of, “It's not going to happen to me, because things like this don't happen to people like me.” I think just a little more reassurance. But kind of false reassurance that medicine can solve all the problems. It never occurred to me that medicine couldn't fix something. It didn't strike me as maybe this actually could be something that they can't solve.
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> I think I was primarily just thinking that medicine is going to solve the problem, because no one in my family had ever been *really* sick, that I

> could remember, where medicine had not helped them get better. I just had this belief that there was going to be some pill or treatment or cream that would solve the problem. It was kind of like, “Oh well it will be fine. I'm appalled that I have a ringworm in my head potentially, but I'll be fine. The medicine is going to take care of it." And the physician’s assistant was telling me, "We're not going to let this happen to you." So I was like, "Well the doctor said it's not going to happen to me, it's not going to happen to me."
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> And then two weeks goes by, they come back and they said, "It's not ringworm." The treatment wasn't working. The hairline was getting worse, so they immediately sent me to a dermatologist who confirmed that it was alopecia. He put me on prednisone, but by that point like two weeks had gone by and I had lost so much of my hair that my mom was making me walk around the house with a bandana.

While Ashley felt reassured, very quickly one of the conditions that shocked her – AA – would be impacting her life. Her AA was progressing rapidly.

The initial impact on Ashley’s life included limitations within her own home, as if she was socially ostracized from her very family. This had both positive and negative side effects. In addition to having to wear a bandana, Ashley shared:

> My mom wouldn't let me go in the kitchen because my hair was everywhere. There was one element of glee because, I was like, "Sweet! I don't have to help with cooking!" But I still had to do dishes, so it didn't really help. My sister would help my mom cook, and I had a little brother who loved being in the kitchen too at the time. So everyone would be in the kitchen. We lived in an apartment at the time, which had an open layout so there was like a tile floor and then a divide. So my mom was like, "You need to stay on the outside of the tile divide." It was almost like a physical barrier, where I would have to sit in the living room while the rest of my family, my entire family would be in the kitchen and I would have to sit in the living room, which was still technically the same space. I wasn't necessarily divided, but it was almost a symbolic divide where you can't cross the tile. I remember one instance, we had a big room and then there was a hallway that went down where all the bedrooms were. I was going down the hallway, and to do that you have to walk through the kitchen, but it's like on the outside of the kitchen. My mom was like, “What are you doing? I told you to stay over there.” And I was like, "I'm going to my room." It was the symbolic divide.

> My hair was orange when I was losing it. I remember there was orange hair all over the house. And I had white flannel sheets, and I would get up in the morning and it would just be orange all over the sheets. And my mom would make me get up 15 minutes earlier than she would make my sister get up and I had to vacuum the hair out of my bed, because there was no other way to get rid of it because the flannel and the hair, it just stuck together really hard. So I just walked around with this bandana on my head, and just my hair continued to fall out in profuse amounts.

There were spaces from which Ashley was precluded from occupying, because the shedding was happening at such a rapid pace. Ashley explained how the rapidly thinning hair created another distinction between her and a sibling – a different wake up time and a new routine.

Ashley also talked about the caring and support she got from her family while going through the process of rapidly losing her hair.

> Losing your hair can actually be kind of painful. I would hang my head off the bed and you know those little tingler things? My mom would use her fingers or use one of those tingler things to massage my scalp because it was achy. I don't think painful in the sense of what we consider pain is an accurate description of it, but it was a hurt so good kind of feeling when she would massage it. It was like, "Oh, I need a massage." My hair was achy, like how you have an achy muscle and you need to go get a massage. Once my hair was shaved off, I still had a little bit of that achy feeling when I touched my own scalp where it felt like it was in flames.
> I got my first wig - my grandmother came up and bought me a really terrible, terrible, terrible wig. But, that was the only one that was available in our town. She also ordered me one of those custom Peggy Knight wigs, which by the way are terrible. They may have gotten better, I don't know, they suction on to your head and in order to suction you can't have any hair growth whatsoever.

While there were limitations to what could be done – they could not undo the pain or hair loss – they tried to help as they could.

Ashley explained a personal reaction at the time was to deny the experience even to herself. She symbolically did this with photographs.

> When my hair was falling out and it got so bad I had a - you know how you can like have a fringe, like bangs - I had a little piece right here on my forehead and it was completely bald all the way around it. So it was like this little island. I have one photo of it, but I was into scrapbooking in high school, and all of my photos of me going bald, I cut around the hairline and cut all the balding out of it. I covered it with like stickers or something. I just didn't want to remember that time in my life. I just didn't want to see, and I didn't want other people to see what I looked like when I was going through it. So I don't have any photos of me, I think the only one I have left is probably that one little one where my hair is just this little piece; it was just everywhere.

Ashley was almost trying to erase the experience from her memory. She explained some of the thoughts she was having at the time, further revealing concerns about femininity and attractiveness:

> From my own experience, I thought, "How, how am I going to get a boyfriend? How are boys going to like me? How am I ever going to be pretty?" And, "Is anyone ever going to want to have sex with me?" I remember having this thought, "No one is ever going to want to have sex with me." And, when you have those thoughts anyways and you have hair, that's one thing, and then suddenly within a very short amount of time you lose all of what you feel, and I strongly *emphasize* the word *feel*, you lose what you feel is your femininity. I would say the hardest things to lose to date were my eye lashes and eye brows. When I was in high school and I lost all of these features, suddenly I was like, “How do I identify as a woman now? Or as a young woman?” Because I no longer have these things.
>
> And I remember thinking when I was in high school, I wish there was a magazine for people like me who don't have hair because nothing in these magazines pertains to me. Those articles are like, "Make boys like you." They're, they're like, "Toss your hair a little bit. Flirt with your eyelashes." You know, "Add a little extra mascara." They're all things that I can't do. And everything is geared towards this idea that hair equals being feminine. And when you don't have it you kind of are lost as a woman in the world. What does this mean for me? If I don't have this then I must not be feminine.

Ashley was troubled by not being able to meet the ideals of femininity. She was helpless to meet socially defined expectations for what it meant to be a woman, and longed for alternative representations of beauty.

Not only was the naturally occurring hair loss out of Ashley’s control, but her family also acted to take some of the control away from her as well.

> My mom suggested that I shave my head because it was getting so bad, and I was losing so much. She tried to put a positive spin on it: “Let's invite your friend.” We invited my sister's best friend who coincidentally was also on prednisone at the same time for a different illness. So I kind of had that support system with her. My mom ordered pizza and had pop. She bought some clippers that I still have to this day. I told her, just do a little bit of a buzz cut, kind of like a short military cut. And they started to shave my head and I was just, you know, crying so much. I was like, "Just do a little bit, let me see." And they were like, "No, just let us do this, you can see when we're done. They held me down in the chair, and then shaved my head to my scalp. I got up and I went in the bathroom, and I was completely bald to the skin. I think the act of being bald itself wasn’t what was traumatic for me, what was traumatic was being held down and being forced to make this change.
>
> When you go through it, some days you just want to be normal. I didn't feel normal for a long time. And I think shaving my head in the manner that my family did – like I know they had good intentions and that they were trying to help me get from A to D and make it as painless as possible – but I needed to get there in my own time. My own experience, it's hard to say whether or not that truly helped or if that aggravated my growth or deterred it a little bit. It’s like when you get a haircut, and you're like, "Okay, I want to go a little bit shorter," and the person chops off 6 inches. And then you're like, "Oh my God! What happened to my hair? Oh my God!” and hysterically crying. Well, imagine the little bit of hair that you do have left, and now you have none. It's the same feeling, but on a little deeper scale because your hair might not come back. Maybe I wanted to brush my hair a little bit more. And, yes, I would have collected a shit ton of hair in my hands while it was brushing it. I can't truly liken it to like an amputation, but it's a loss. I think I see it as losing a limb. Like I remember when the Boston marathon bombings happened, and there was a mother and a daughter; the mother lost her leg and the daughter almost lost her ankle. I remember following the stories really closely, and thinking how the mother losing her legs altered her life in such profound ways that she would – not that she would never recover – but that it would take her a long time to adjust to it. I think that's exactly how alopecia affects women

> in particular, or my experience as a woman was where it was such a profound loss for me that I didn't, it took me 10 years to find my new normal.

Ashley reflects that this life-altering moment of sudden and unexpected change took away her chance to knowingly say goodbye. Catching her off-guard, she was never again able to do familiar hair rituals. She recognizes a positive of this change was a new physical sensation.

> After they had shaved my head, I had gotten into the shower and I remember very distinctly the feeling of water bouncing off my head and thinking, “This is cool. I've never felt this before.” And being very aware of the sensation of what it was like to be bald, stepping out of the shower, and what it was like to not have to wrap your hair up in a towel and dry it. It was almost like an, not an out of body experience, just one that was hyperaware of every droplet that hit my head was splattering. That was the only positive feeling that I felt that day when my head was shaved. And feeling the water bounce off my head was almost like a rebirth in a way. “This is different, but it feels good.” Even though I knew that this wasn't going to feel good tomorrow, it was like I could go home every night and I can feel this sensation. And it's different, and it's new, and I like it. And there was one thing that I could look forward to at the end of the day when I went into my life, and into school and into the roles, and had all these negative experiences. It kind of made me feel more alive, and aware of where I was at that moment in my life. And it wasn't something that I was like, "Oh my God I'm feeling this because I'm bald!" That wasn’t in my head at all. Obviously, I knew I was feeling this because I was bald, but it felt like, I can have this experience that other people aren't having right now because of something that's happening to me. This is the one thing that I can turn positive at this stage of my life.

Ashley found this new physical sensation was pleasant, and she appreciated that it was unique to her.

Ashley explains that some experiences with the medical community were disappointing, and that she feels the treatment she used had a cost greater than her original symptoms.

> He put me on prednisone. As a kid, I'm like "This medicine is going to work, medicine always works, I'll be fine." The prednisone started to kick in, I was on like 60 mg a day for 6 months, and I think I gained about 60 lbs. over the course of the treatment period. Prednisone is a bitch. I was tired. I was depressed from losing my hair anyways and so that didn't help, I was too tired to move, I was sluggish, I was hungry all the time. I would eat so much food. And I was gaining weight from the prednisone alone, and then I was eating a lot of extra food because I was on such a high dose of it. I’m losing my identity of what it is to be feminine and to be a woman from losing my hair, and now all of the sudden I’m turning into a balloon. My face was a moon-face and whatever feminine features I had at the time before I started prednisone were absolutely gone. Again, I don't have a lot of pictures from when I was going through alopecia because I destroyed them all. But I have one and you can barely see my eyes because my cheeks are so puffy. And prednisone makes you irritable. That also probably caused a rift between my sister and I because we shared a bedroom, so it was a very small bedroom, and it's just not a good drug to be on.
>
> My body permanently changed. I had gone through puberty in like, 7th to 8th grade. So I was starting to develop breasts. I had gone through I think the majority of the stage of it. Prednisone is probably worse than watching your hair fall out. But when you're losing your hair, you'll do anything to keep it. It's not like I wasn't told that I would gain weight, but doctors have a way of minimizing the risks. I think it's kind of a decision that's important because, especially at that age, what's worse: losing your hair and you just lose your hair, or losing your hair and you're fat? It's a double-edged sword.

She was surprised by the weight gain, and did not fully understand the risks involved with her treatment because of implicit trust in medical providers and never before knowing a condition to be untreatable. Ashley was also surprised by how ineffective the treatment was for her alopecia. She wishes there was more protection for her as a youth.

Ashely described her experiences with wigs were largely disappointing as well, in part because the quality and availability of wigs for her was sub-par.

> The first wigs were terrible, and it was synthetic hair and so it was like really shiny. So I had this awful wig. The store that I went to, there was only one in my town, and they were geared mostly towards like elderly

> women that were losing their hair. So there were only a few styles that I could choose from, and I was really concerned about, "I don't want to choose anything that’s not going to be believable." I put on some really long styles, and my hair was like bob length at the time, so I was like, "I can't go back to school next month and have people be like, 'What happened to your hair?'," I wanted to be as normal as possible. So I chose the only one that was bob-length. I felt a little more comfortable just because I had something that made me feel, in my mind I guess I thought no one is going to notice, which is so foolish in hindsight. Because it was such a bad wig! But people were relatively silent about it. I wouldn't say they were nice about it, even as an adult when I tell people that I wear wigs, they're like, "Gasp! Oh my God, you can't tell!" And I'm like, “Please, you can tell.”
>
> It was a bad wig. It was bad. I wore my synthetic hair wig when I worked at the Dairy Queen. I would have to be by the burger machine and the fryers. And synthetic hair frizzes when it's near heat, so the whole bottom of my wig looked like this tangled web of synthetic fiber. So maybe from the front it would look okay, but the back of it – from the heat of that and then from my own body from just being in that environment – made my wigs like deteriorate so quickly that you can't reasonably pass off as, "I'm not wearing a wig." They were so bad. I remember I left my wig in my car once when I was cheering at a football game. I left it folded up in the back seat and the heat, it was out in the sun, but when I got home it was so hot that it permanently altered the way that my wig sat because it was folded in half. I was like, "Well, there goes another wig." I had to go find another one. I hated wig shopping.

Ashley hoped for a wig that would maintain her appearance before AA, and perhaps allow her to keep it private. In her eyes, the quality of the wigs available to her at the time were so poor that she was unable to hide that she was wearing a wig.

Ashley soon had to return to school, and face her high school with a new and different appearance. She explains she already received extra attention for being different.

> When I think back it all happened so fast within the span of a month, from when I found the spot to when I shaved my head to when I got fitted for my terrible Peggy Knight wig. I went back to school with an awful, awful wig before I had gotten the Peggy Knight prosthetic. It was just this

> terrible month. We had moved from Texas to Minnesota right before 8th grade. I was still really new to the school, and not really found my place. I was made fun of in school because I had this really thick Texas accent, and people would ask me, "Do you ride your own horse to school?" I'm like, "I don't have a horse." They just made fun of me, and here I lose my hair. Then I have to go back into this environment where people were already not as kind to me as they may have otherwise been. Now I look really different because my eye lashes and my eyebrows had for the most part fallen out before I started school again that freshman year.

The AA further separated her from her peers, when they already had been pointing out her differences. Ashley explains the AA also presented difficulties in her extracurricular activities as well.

> I was also a cheerleader in high school. There is some board for cheerleading where they set rules and stuff. I would wear a bandana when I would go to practice, because I would get really sweaty and the bandana would absorb all the sweat. I was told that I couldn’t wear a bandana during school, during gym hours, or during basketball games or football games, or whatever I was cheering for at the time. I didn't have any options for what I could wear. We had to take this all the way up to the state board and get special approval for me to wear a bandana. I was told I had to wear a wig that can't fall off, which means I had to wear that awful Peggy Knight wig. They suction onto your head, but you have to shave your head every single day, like if you have any sort of hair it won't stay. And it doesn't breathe, so you get sweaty, and the wig will just shift and your part will be like over here and it'll keep moving back and forth because it gets so sweaty. They do a relatively good job of staying suctioned onto your head, but when you get really sweaty, even if someone like yanked on it, it is going to break the seal and then it could come off. It's like, what's more embarrassing? Like, having my wig fall off in front of thousands of people or wearing a bandana? And I wanted to wear a bandana, because it was more comfortable. I could stunt, I could tumble, I could be a cheerleader. When I was in a wig, I couldn't be that. So we had to go get like this level of approval for bandanas. So the only thing that I was approved to wear was a bandana because it was tied really tight against my head. And then suddenly, I felt like a biker. Like a biker in a gang, you know? That doesn't make you feel feminine at all. I have boobs, I have somewhat of a womanly body, but not really because I'm on prednisone and so now I'm just this big ball of blimp, and now I have to wear a bandana and suddenly I feel even less feminine than I did before. So for a long time that's all I wore.

As a cheerleader, Ashley actually preferred for the AA to be somewhat more visible with the bandana than the wig, because she preferred how it functioned. Ashley fought for a way around rules, winning the right for her to be more comfortable. She had to deal with the unintended consequence, however, of feeling less feminine in her chosen look.

When there was teasing in high school, Ashley found some support from her sister and her friends. She found the staff's response less helpful.

> There was a guy that sat in the back of my math class who would threaten to pull my wig off every day in math. To this day I'm terrible at math, and I think a lot of that is because I just could never focus because of this person who sat behind me. I told the teacher, and the teacher was just like, "Stop it. Stop doing that." He didn't actually take any steps to change anything or, like move seats or anything. I remember him, he didn't pull it off, but he did tug at it once, which scared me enough. I left the class and I ran and I saw my sister in the hall, and I was crying. She went into the bathroom with me and I was just like hysterically sobbing, like, "He tried to pull my wig off," Then, some of her upper-class friends that were boys came out and said, “We are going to take care of you, take care of the situation,” that kind of a thing.

The teasing was so disrupting that Ashley identifies herself as having long-standing difficulties because of it. The distressing experiences were a lot for Ashley to deal with as a teen, and she sometimes struggled with feelings of hopelessness.

> I remember having some suicidal thoughts, but not to the extent that I would ever act upon it. But I remember thinking, “Is this going to be my life? And, if so, what's the point?” If every day I'm actively working to try and hide this, and people are making fun of me for just existing, “Why would I want to continue?” Ultimately, it comes down to like, “How do I relieve my suffering?” Because you suffer a lot. You have that thought of, "What am I going to do? What's the point? How do I relieve my suffering?" And you can't find a solution, because you're going bald, you're not feminine, people are making fun of you. You're fat, you eat too much and then here you are at home, not being allowed in the kitchen. Then, what's the point when every facet of your life is affected?

Ashley felt helpless and overwhelmed.

While the rejection from some peers and family was difficult to bear, Ashley found acceptance and purpose with an alternative group of peers.

> I think I started to focus more on what I felt were my talents. And I was really active in like the choral society in our school, and I did a lot of theater. I felt more accepted, like especially in the theater department, of course I felt accepted there. Being with the quote-unquote weird crowd made me feel more accepted because even if I was perceived as a little bit strange for whatever reason amongst my classmates, I had talents within those areas where, in the choral society I was in all-state, I was in honors, I was doing all of these things that I was good at. And it didn't matter whether or not I had hair, or was popular, or I had to wear a bandana. None of those things mattered because it wasn’t about that. It wasn't about this perception and putting forth this persona of, I have to look like the school spirit, I have to abide by the schools rules. I can be a little bit more flexible. So, when I found those departments and things where I could flourish in what talents I did have, I felt a little more purpose. I found my purpose, I guess, in high school.

Buoyed by the acceptance of peers in the “weird crowd,” Ashley could focus on getting appreciation and attention for the things she did well. She mentions finding purpose, perhaps giving her something to look forward to – an area of life unaffected by her AA. This is in stark contrast to her aforementioned suffering as a result of feeling like AA had negatively affected every part of her life.

Still, there continued to be reminders that Ashley was different, and that others were not that kind. She explains an experience with her younger brother.

> I have a brother that's 9 years younger than I am. When he was in elementary school, I would go to pick him up. One day he asked me to not come and pick him up unless I was wearing my wig. And I asked him why, and he said that his classmates made fun of him because he had a bald sister. He was in 2nd grade or something. He didn’t' know what he was saying, but I just cried the whole way home. That's a hard thing to hear because it's not directly affecting me but it's affecting my brother. He's just trying to make his life a little more stable and a little bit easier.

It was hurtful to see her AA was affecting her brother.

While in college and working, Ashley continued to experience adversity and rejection when she exposed her baldhead.

> When I was in college I was working at a salon or a spa of a resort. I worked at the spa during the day, and then I worked at the bar at the night. And at the bar I would wear my wig, because I would get more tips that way. And at the spa I would wear my turban. I was wearing my wig to begin with at the spa, but as the summer went on it got warmer. I think the spa owner really had it out for me for some reason. She'd give me 8 hours of hot stone massages back to back, and my room would get warm. I would get warm, and I'd be wearing this wig. So I stopped wearing the wig and I started wearing a turban. I followed the dress code, I came to work on time, and she would say "Oh, why aren't you wearing your wig?" And I was like, "It's too hot. It's 100 degrees outside, I'm doing hot stone massages all day. I'm hot." And she kept trying to bring it up. One day she said, "You need to wear your wig when you work here. I hired you to be in the massage service." And I said, "I'm still doing my job, I'm just not wearing a wig." She said, "People are uncomfortable with you because they think you have cancer and you're massaging them and they feel bad." And I said, "Why, if I had cancer, would I be working as a massage therapist and be your most requested massage therapist at the spa?" She kind of kept going with it, and I said, "I think the person who has the problem here is you." And she said, "I don't have a problem with it. I think it's fine." And it kind of went off in that direction and I eventually went to an attorney to see is this legal. No, it's a form of discrimination.

Ashley fought back against her employer, even getting verification that her treatment was unfair. Her sharp retorts suggest the experience left her feeling angry, and likely hurt.

> On another occasion I was working at a gas station in my hometown, and I was working the kitchen making pizza. Then sometimes I would have to go in to the front to work at the register while some people took their lunch breaks. At the time I was wearing synthetic wigs, and synthetic wigs when you expose them to heat they start to frizz and they'll be ruined because of heat. So I would wear a bandana while I was cooking. And then one day I took the bandana off when I went up to the register, and the manager came up to me and was like, "Why aren't you wearing your bandana? What happened?" And I said, "I don't want to wear it?" And she was like, "Oh, do you want me to tie it for you, like I could tie it for you."

> And I was like, "No, it's not an issue with tying it, I just don't want to wear it." And she was just insistent. She didn't go to the degree that the spa woman did, but there have definitely been instances *where people don't want me to be myself* because they were afraid that it would affect their business or whether or not they were uncomfortable, whatever the motivation was behind it. I'm not entirely sure. But, it happened to me enough times where I know from personal experience that I'm better off wearing a wig in a professional setting.

By saying “people don’t want me to be myself,” Ashley suggests that disguising her AA feels like disguising herself. Her employer’s desire for her to hide her hair loss at all times might feel like a personal rejection. She feels the lesson from these experiences is that she should wear a wig at work, and continues to do so to this day.

Eventually Ashley moved across the country and away from the small town. At first she continually hid her AA with her wig to experience life free from the label of the “bald girl.” When she eventually felt compelled to reveal her AA, she was pleasantly surprised with the acceptance she received from her new community.

> I had moved to San Francisco, and I think when I first got here I didn't tell anyone about it. Only my roommates knew I had it. I did that strategically because I wanted people to get to know me as an individual before they got to know the condition. I soon found out that that's not sustainable, to hide this aspect of your life from people that really care about you. Especially your friends, because your friends don't care. I went through this period of pretending like I had hair and that there was nothing wrong. And that was really hard and unsustainable because no one wants to wear their wig 24 hours a day, 7 days a week. So when I finally started to tell my friends that I had it, that's when I started to feel more accepted. My friends were of varying ages, anywhere from the same age that I was to a little bit older to 60. So I had a lot of different reactions that were all pretty positive. And they just gave me that extra boost of confidence where I wasn’t the bald girl, like how I was when I was in high school and my home town where people know me because of this condition. It was very visible. I was the only person in my community who had ever had it that we had known of. Coming out to San Francisco and being able to step away from that, and then realizing that it's not that great to only wear your wig.

> I've lived in my neighborhood for 7 years, and everyone knows me from my turban. Everyone just has really positive reactions, and they are very friendly. I think I've almost felt this embrace of alopecia, because I feel finally like I can still be feminine without having hair. I had to find out how to be feminine in my own terms and not necessarily what society told me was feminine. Like in magazines, and seeing the long hair. How do I create my own self-identity that works for me and not for society? And part of that was finding hats that made me feel comfortable, and confident. And changing up my style a little bit. And, obviously San Francisco is like super eclectic. I have some really funky turbans that if I go home to the small town people will laugh at them because they are huge. And here, people are like, "That's so couture." And it's just a different environment. So I think part of creating that new normal was finding an environment that worked for me and surrounding myself with people who encouraged me to be myself.

Ashley experienced what she had been looking for a life with AA fully hidden. In living that way, however, she learned how tiresome it could be. No longer wanting either to be an outcast or to be completely hiding, Ashley experienced a pivotal realization in which she learned that what she wanted more than anything was to be accepted with the AA. Her new community has embraced her that way.

Ashley explains another change in her experience was finding a comfortable alternative to wigs.

> Once I came to San Francisco, I found this woman on Ebay who makes these turbans. She started selling them for like, $2.50. She was a nurse in an oncology unit and she said, "My patients always told me that hats are very hard to come by, and they're very expensive." And they really are. So she's like, "I like to do this in my spare time. I'm just trying to help people." So I have a drawer full of these turbans that I wear, and this is my alter ego. And after work, and on the weekends, I'm part of a charity cheerleading organization and they call me "Turban Girl." And my fiancé calls me turban-pie. It's just kinda this part of my personality where I wear turbans. And when I started wearing them, then I felt a little more feminine, because I can wear these with my nice clothes. I can wear them with nice earrings. Where, if I'm wearing a bandana, then they look a little mismatched and weird.

Ashley found turbans enabled her to feel feminine, be trendy, and be comfortable. She saw this look as a new persona, a new way she could present herself. The community that embraced her took to labeling her again – but this time, as opposed to being the "bald girl"– the turban-referencing nicknames are playfully used to express caring and acceptance.

Another persona for Ashley is when she has a wig and lashes on, which tends to bring her compliments and positive attention.

> People would always tell me and my sister, "You guys look so much alike" when we were kids. And then as adults, and like, no one ever tells us we look alike. I have a photo of me with fake eyelashes on and my hair done and I'm going out to a party. I think I posted it on Facebook and everyone wrote, like, "Oh my God! You're stunning!" Like, "You look so beautiful! You look so much like your sister!" And, I'm like, it's eyelashes and eye brows. Because when I wear fake eyelashes and I have my eye brows tattooed on, I look a lot like her if I have the whole getup on. But let's be realistic, I don't have time for that. So, I don't do it. And my mom when my sister got married was like, "Are you going to wear fake eyelashes for your sister's wedding?" And I said, "I don't know." And she said, "I mean, you're just so pretty with them." And of course I'm like, is that a back-handed statement? Like, you know, it's kind of like a double-edged sword. I know that she means well.

Ashley recognizes that the positive attention, while nice, might also have negative implications about her everyday appearance.

While Ashley had found acceptance in much of her social life, she still had a greater fear of rejection and concerns about attractiveness for romantic relationships.

> When I was single I thought about my alopecia all the time. I had intimacy issues to a certain degree because you don't want to be rejected for this thing that you have no control over. When I was single, I thought about it all the time because my whole thought was, "How is anyone going to want to date someone who has this condition?" When I was single, it was totally all I thought about.

The guy I dated before my fiancé, I had dated him for 3 months or so. We had a really great connection. I have this rule in my head that I would give the guys I dated 3 months to get to know me, and then I would tell them about my alopecia in the hope that 3 months was enough time for them to see whether or not they would want to be with me. We had gone to the symphony or something a week before, and we saw this elderly couple. He made a comment of, “That's going to be us in 40, 50 years.” I had gotten us tickets to go see the symphony the following weekend. I was at his house and I had told him about, "Hey, there's something I haven't told you about myself. I have this condition, I've had it for a long time." And I had this like speech that I would have in my mind, which of course never played out the way that I imagined it to. And, then I told him, "I'm not ashamed of this, but this is something that you should be aware of. And I'm comfortable with myself." And he was like, "You're beautiful the way you are." I was supposed to stay at his house that night, he had asked me to bring some clothes over. He was like, “I got some work to do, so I'm going to drop you off at your house." I was like, "Okay, I know where this is going." So he drops me off at my house.

I had texted him later and he didn't respond to me. He did text, "Hey, can I swing by your house tonight to talk to you?" He wanted to come over and talk to me. So I took a shower, put on my makeup, got myself ready, made myself look as best as I could. Because I knew what he was going to do, and I was like, "Eat your heart out." He came over and had a bag of my things, and he was like, "I just don't know where this is going. You're a really nice girl, but I just don't see this working long-term." I was like, "Really? I would rather you just tell me to my face. I know the reason you're breaking up with me and I want you to say it." Then he got really quiet and he said, "I thought about what you told me, and I'm just not okay with that. That's not feminine, and that just is inadequate," basically is what he said. I was really hurt, but I held back my tears. And that was the last time I saw him. I was so hurt by it, but I didn't want him to see me cry because I didn't want him to know that that was my biggest insecurity. So I tried to hold my head up high, and the second I shut the door I burst into tears and called my mom.

For weeks afterwards I just thought, "He's going to turn around. He's going to be like sitting on my step when I come home, and realize what he did wrong." You know, wishful thinking. And, and that really destroyed my confidence in myself because that was my worst nightmare coming true. And, I had never had that experience with other people to that degree where I had been in a relationship with someone to that extent and they were just like, "You're not enough for me because of this." It was really, a really painful, painful experience.

The rejection was especially painful because even though he knew her, he was willing to give up what he knew and appreciated because of her AA. This was her worst fear realized. Ashley was powerless to do anything, just as there is nothing she can do about having AA. She reveals in her retort that she had already developed skills to cope with judgements from others. She turned to her family and community for support.

> I called one of my friends and said, "Hey I have an extra ticket, you want to go with me?" And he said, "Sure, I'll go with you." And then we get there and he says, "I have a feeling that I'm a stand-in for someone. What's going on?" And, I told him kind of what happened, because I had not shared my alopecia story with him. I kind of gave him the soft version, and I was just like, "I was dating this guy for a couple months and I told him something that had happened to me when I was a teenager, and he didn't like it and broke up with me." And I said, "I feel really hurt, I feel really beaten down by this because there's nothing I can do. And I think that I'm a quality person, but I'm obviously not quality enough. I feel like maybe I should stop dating because I don't think I can like look another person in the eye and risk having the same reaction." That friend said, "If you stop dating, you let everything that he said to you become true. You're letting him win. You don't have to date someone seriously. Go on a date, let a guy tell you you're pretty, let him buy you dinner, and go home. And do that until you feel like you're ready to be in a relationship again." And, so I did.

The friend’s encouragement and empowerment was enough to get Ashley dating again, but she was more hesitant and careful. Her next dating experience, however, provided acceptance.

> And the first person I went on a date with is my now fiancé, my rebound became my fiancé. I couldn't tell him for 7 months. I waited to tell him about it. Even when I was first dating my fiancé, I didn't want him to touch my head. And he knew that something was wrong and he was trying to figure out what it was without directly bringing it up. My fiancé, when I told him about alopecia, I dated him for 7 months before I told him that I have this. And when I did, he was like, "Oh, I know." I was like, "I wear a wig." And he was like, "Oh, I know." And, I said, "Well, what do you mean you know?" He's like, "I've known since our second date." And I'm

> like, and in my mind I'm like, "Well I have good wigs, how can you tell?" Well, you can notice the eyelashes and eye brows when you're that close to someone. You can tell.

The dating experience with her fiancé was very different. Ashley experienced someone who was not troubled by her AA, even though he knew from almost the very beginning. He accepted her.

Ashley now has acceptance in her romantic life, but she is still concerned about acceptance from others and the limitations she has because of wearing a wig. Even the people who accept her are not automatically aware of her limitations.

> We went to like a great America Six Flags with my fiancé’s sister. We haven't told her about the alopecia yet. I'm deathly afraid of roller coasters, so I wasn't going to get on them anyways. But I was like, "I can't get on some of these rides that even aren't roller coasters because the speed will take my hair off." And he was like, "Oh, I'm sorry, I didn't even think about that. It wasn't something that came to my mind." And that goes back to where people say, "If I had alopecia I would do this." I'm like, if you had alopecia you would have no idea what to do because there's constantly obstacles to how to keep yourself comfortable and how to keep other people comfortable.

Ashley implies that maintaining her appearance is as much a part of her concern for others as it is for herself – it keeps others, perhaps strangers, more comfortable. She described a situation in which the secret of her AA might have been revealed. When a stranger lift’s Ashley’s wig, she reacts instinctually and emotionally:

> Most women would put their hair up in a ponytail when they're doing things, and I can't do that. Once I was at a birthday party at a bar and I was like, "Oh, it's so hot in here." And this girl that was also at the birthday party that I didn't even know took the tips of my hair and was like, "Here, just lift it up." And I was like, "What the fuck are you doing? Stop touching me." She almost lifted my wig right off of my head. She knew that she did something wrong because I had such a volatile reaction towards her. That whole night I was so self-conscious I wanted to leave. I was like, "Now all these people know that I'm wearing a wig."

> I don't care that people know that I wear a wig, but I don't want people to think that I'm normal and then suddenly, like, if my wig were to fall off or something that would be quite embarrassing. I think it would be embarrassing for anyone. But I think nowadays, like in that setting for example where I was at a bar, I know people would have laughed at me. I know people would have mocked me without understanding what the underlying reason was for me wearing a wig. It's hard to explain because I think that I'm well-adjusted to alopecia, and I think this is like one of those lingering insecurities that I might always have. I think there's a lot of different things that could go wrong when you're wearing a wig. Thankfully I never had my wig fall off of my head in a public setting at least. But I think about how would that affect me. Would I just bend over, pick it up, and put it back on? I don't think I would do that. Would I bend over and leave? I don't think I would do that either. I don't really know what I would do. It's kind of like when people say, "Oh if I had alopecia I would do this." Like you don't know until you're in that position, and I don't know what I would do. So it's just like unknown territory.

Ashley seems to describe that she has made peace with her AA, but still experiences anxiety from the possibility of being ridiculed if the wig fails. The wig still does not feel 100% safe.

Ashley explains concerns about superficiality and stereotyping are something that she expects to face in the future with AA. She especially expects to be confronted by these difficulties as she gets to know her fiancé’s parents, who are from a different culture.

> I haven't met my fiancé’s parents yet. I think I'm going to go through a regression period when his parents find out about this. I think I'm going to re-live some of my more painful experiences. They already have a lot out against me because I'm not from their culture. I'm really nervous about telling them. My fiancé assured me that he would be the one to tell them about this. But he was like, "I want them to meet you the way that I met you where they get to know you as a wonderful person first." And I was like, "I don't want to know what they say about me when they find out about this because it might not be very kind. And, I want to have the purest possible view of your parents for as long as possible, like I don't want to hear anything bad that they say about me.” And I'm like okay, I have to think about all these different scenarios of, "What if we go

> kayaking? What if they want to go swimming? What if they do these things? What do I do?" I don't know what to do if they want to go swimming? I mean, I doubt they will, but I can't swim with my wig. It will definitely come off. I think I'm going to regress a little bit. And I think I'll experience periods like that throughout my life.

Ashley has reached a point where she is okay with her AA, but she still recognizes that other people might have negative reactions. She is concerned about what her fiancé's parents might think of her because she wants to have a positive and supportive relationship with them. It would be disappointing to find out that is not the case. Ashley also considers how AA might bring about rejection for her children.

> When I think about having kids, how is this going to impact my kid? And even if they don't have it, they might still experience the effects of it as a school child the way I experienced it, and the way my brother experienced it.

Ashley feels she will continue to confront difficulties with her AA, and that for her she does not see a moment in which her thoughts and feelings about the AA will change.

> I don't think that I'm like one and done, I beat the emotional demons of alopecia. I definitely don't think that. I think I'm going to have a life-long struggle with it based on the experiences of people around me. I think the last interview I had referenced the Boston bombings and someone losing a limb and equating alopecia to losing a limb. Those people, even if they have prosthetics and years of therapy, probably are not going to get over that. And I don't think that I'll ever truly get over alopecia. I think I can develop some coping techniques to deal with the situations that it puts me in throughout my lifetime. But it's still a trauma. You think about it less as time goes on but it's not going to go away.

Ashley explains the meaning of her experience with AA is something she is still processing, but that she hopes that it has made her more empathetic and better able to handle adversity.

> I have often thought, "What would my life be like if I didn't have this? Who would I be as an individual? How would I treat people?" I like to

> think that I treat people better because of my own experiences, but how much does this change me? I think that it changes me a lot. And I hope that it changed me for the better. I like to think that it changed me for the better.
>
> What sense alopecia does make to me is that I think it sets the stage for a lot of harder experiences in my life. In particular like this experience that I have with my fiancé and his family. Alopecia really makes you confront superficiality in yourself, in others, in the environment that's surrounding you. And you can choose whether or not you want to live in those parameters. Alopecia has taught me how to deal with superficiality, and I think it set the stage for some of these bigger experiences that are happening in my life right now.

Ashley further shares that she feels it has broadened her perspective, especially about superficiality. Having an awareness of superficiality has given her the ability to choose not to let it dictate her actions. Even with her perspective broadened, however, she still has to face that others may not share the perspective she does.

The Typical Day

Summary. In Ashley's typical day, the prominence of her AA varies. While struggling with a torn wig, the reminder of her AA is constant. With the new wig, the AA is a more unconscious experience. It primarily comes into her awareness when uncomfortable, or being threatened by the potential for others – strangers or colleagues – to know her secret. Those experiences are sometimes met with a strong, even "volatile" reaction. Still, Ashley does not shy away from social experiences and even shows her AA to others in safe settings, such as her home, relatively free from concern.

Detailed description. Much of Ashley's typical daily experiences with AA involve tasks that would be relatively unfamiliar to people who do not have AA. But for her, those tasks are familiar and routine.

> When I get up in the morning I wash my face. I put my moisturizer on. And then I usually go back and I lay down. I have this little massaging thing, and I get a little massage in the morning. Then once my moisturizer has set in, I have my, I don't have eyebrows because I have universalis I don't have eyebrows or eyelashes. I have my eyebrows tattooed on, but they faded a lot. I have this henna based product that's kind of a stain. I guess it's drawing on my eyebrows, but I'm basically just penciling or filling this gel in over the existing tattoo. I have to line it up really nicely and make sure that they're even and let it set, soak in. That takes about 5, 10 minutes. Otherwise you don't see my eyebrows because they faded so much. And then I'll put my makeup on. Then I have to take my wig and wipe it down. The perimeter on the inside is lined with silicone for the grip. I have to use a paper towel and some rubbing alcohol to restore the grip and remove the oils from the silicone. Put the wig on, line it up, brush it out, put the strap on, put the elastic band on the head, and then grab my oatmeal and run out the door. So, I mean it's, it's not like super tedious I guess, it's just, I guess because it's just routine now so I know what I have to do.
>
> Taking your wig off is like taking your bra off at the end of the day. Like "Ah!" It's so good. Then I just massage my head. There's usually just popping it off my head, brushing it, and putting it on the mannequin. I think the process of that is usually more extensive in the morning, unless it's on the weekends when I have to wash it. I take a shower right away when I get home. Usually once I take the shower then I climb into bed.

Most often she might not even think about her AA much on a typical day, with exceptions being when she is experiencing concern about her wig or discomfort as a result of it. Those experiences draw her out of the passiveness with which she typically goes about her day.

> On a day-to-day basis, now, I think about it in smaller ways. If I'm uncomfortable then it's hard to not think about it. I'm an office manager for an investment bank, and right now we're shipping out a lot of boxes. Like we're tearing out our files. That gets physical, and I get warm, and I get uncomfortable. And that's when I start thinking about it, like when I get really warm.
>
> There's all these sensory experiences; having the wind blow through your hair and being concerned about, “Is my wig going to fall off?” Having someone touch your hair. Like someone came up to me at work and

> grabbed my new wig and was like, "Oh it's so pretty." And I tried really hard not to flinch because I don't let people touch my head.
> And when I ride my scooter, I have to be very careful with putting my helmet on my head so that it doesn't tear the hair out of my wig.

There are a variety of potential experiences that draw her out of the moment and catch her concern.

The AA dictates some of the decisions Ashley makes for her leisure time, particularly regarding her dilemma to work out without her wig and simultaneously not disclose her AA to work colleagues.

> Sometimes I go to yoga. Yoga is interesting because my partner just wants to go to a studio by the office. And, I'm like, "Oh, I got to take my wig off and put it in my backpack, and what if I run into someone at the office?" I think about that, what if I run into someone that I know who doesn't know that I have this. I really hate working out because I have alopecia, I really do. I wear a bandana because I sweat so much, but it kind of takes me back to when I was in high school and I had to wear a bandana in cheerleading. I felt very unfeminine because I wore this bandana. I've tried wearing turbans that are moisture-wicking, and it gets in the way. It doesn't work the same way. So whenever I go workout, I have to wear a bandana. And I will make selective decisions about which gym I go to or which studio I go to based off if I know that someone that I know who I haven't told I have alopecia goes to that gym, then I won't go there. Or I won't go at a certain time that I know they'll be there.

Choosing a yoga studio or gym presents another situation in which Ashley’s partner is not as aware of her AA-related limitations. She again prefers the function of a bandana while being active, but while wearing it she struggles with feeling unfeminine.

Ashley described some additional experiences she might have in a typical week, and the decisions she makes about going out without her wig or the discomfort she might feel because of it.

> If I do go out, I'll go to the park or I'll go to the bar. I'm fine going to a bar in my turban if it's a gay bar, but if it's a straight bar I'm not fond of it. I

> don't know why. I'm like, "I have a partner, I'm not looking for someone." But I still feel uncomfortable going to a bar with my turban on if it's a straight bar.
>
> When I go dancing, I have to put deodorant on my head and I'm constantly brushing my hair because the heat sucks all the moisture out of it and I don't want to wash it the next day. I think there's a lot of small indirect ways that I think about it that maybe I'm not immediately aware of that are just part of my routine.

Despite potential discomfort or concern, Ashley still engages in these social experiences willingly.

In the comfort of her own home, Ashley also interacts with strangers on a regular basis. She explains:

> My roommate and I do Air B&B on our third room. The lady that we have staying with us right now; she's like a Dutch hippy, she's pretty cool. She met me when I was home, and I had this clay face mask on and I was bald. I said hello to her. And then the next morning she saw me with my wig on and she was really polite about it. She goes, "Oh, costume change." And I said, "Yeah, this is my alter ego." And, we had a laugh about it. But we've had other guests come to the house. We had a young man who was like, 23, 24 who called his mom and asked what could possibly be wrong with me, and he thought that I had cancer and he thought that I was dying and he felt terrible. He talked to my roommate about it. She was like, "He thinks that you're dying." And, I was like, “That's sweet that he has that much concern for a stranger.” We have these people cycling through our house all the time that I don't tell them that I have alopecia. Why would I tell them that I have alopecia? It would be a really odd conversation to have anyway: "Oh, by the way, I'm not dying. I just have no hair."

Ashley chooses to maintain her home as a safe and comfortable space to be without her wig despite the presence of people who do not know her or about her AA. She feels no responsibility to disclose about her AA either.

Atypical experiences. Ashley described her typical day is somewhat atypical currently because she recently changed from an old wig to a new one. The experience with the older wig included some routines reminiscent of what someone might do to cover patchy AA.

> When I had my old wig, my ill-fitting wig. It had a hole in the back of it that was losing its hair. I had that one for a year and a half or two years or something. It had been shedding a lot of hair, and so I felt really self-conscious because I knew that it was going bald. I felt like I had alopecia all over again. It felt like I was losing my hair because trying to drape it constantly, and you know spray all these different products on it to kind of disguise that it was losing hair. And all throughout the day I would be self-conscious of, is my spot showing? Even though it's not my spot necessarily. It's not something that I can control, it's losing its hair. It's like alopecia all over again. And I had this huge, I would say like a 2 and a half to 3-inch tear in the back of my wig. I would turn around the corner and it would blow the wind and split the hair in that spot. And I would constantly be holding my hair down to keep it from flying because I didn't want people to see that I had this big spot. And I don't have any issues with people knowing that I have alopecia. But, I’m really self-conscious about wearing a wig and someone knowing that I'm wearing a wig. Like if I tell them or if it's immediately visible, and I know with this one that it was really apparent to a lot of my co-workers that something was wrong because of all the shedding on the top of the head in particular.
> When I would get up in the morning there would be this sense of dread of, like, I have to put this wig on and I have to go to work like this and it's not washed, it's not conditioned, it looks like straw but I can't wash it until the weekend. And, "What if the spots start to show?" Not to mention it didn't fit, so it wasn't comfortable. I had to hold it down with one of those elastic hair bands, and I would get home at the end of the day and my fiancé would look at my head and say, "What happened to your head?" Because the hair band was so tight it would make an indent in my head, which you wouldn't normally see if you had hair. So I felt like there were all these extra precautions that I had to go through throughout the day in addition to the regular, combing the hair and trying to make sure that the spots were covered. The shedding of the hair was probably 6 to 9 months of worrying about that.

Ashley again struggled with the greater presence of AA in her life, and worrying about it being revealed to her colleagues. She may be able to live with her AA as an unconscious experience most of the time, but the torn wig brought her back to a greater awareness and concern about her secret being known. To have someone at work know she is wearing a wig is still a concern.

Participant 6

The Life Story

Summary. Bella's description of her first experience with AA exemplifies a change from overall low consciousness of her appearance at that time of her life. While previously her appearance was viewed neutrally, it would take on greater significance and becomes "a bigger deal." Experiences at doctor's visits conveyed something was wrong. She encountered unkind reactions from her peers. Publicly, Bella put on the persona that nothing had changed, but internally she hid feeling that she was an outsider. Bella and her family searched for options to bring her relief. In their search for options, an ill-fitting wig leaves Bella feeling threatened to look even more different from who she feels she is, when all she wanted was to still look "like me." Her hair soon regrew, providing some respite from her self-consciousness.

The AA eventually returned, and Bella found herself helpless to hide her AA. She again feels distinctly different from her peers. Unable to hide it, Bella withdrew from activities that might reveal her AA. She avoided talking about what was happening or how she was feeling. Bella found support and safety – her "sanctuary" – at home with her family. For most relationships, even though the AA was visible, it was never openly acknowledged.

Bella explains that her AA was less extensive in high school, and that not having to hide as much allowed her to feel safer trying new hairstyles and sharing about her AA with friends. Bella told others about her AA, and had experiences contrary to feared expectations. While it had become easier to conceal her AA, she describes an overwhelming concern to make sure the spots were appropriately covered.

After high school, Bella experienced a dramatic change in her AA that resulted in a major emotional change as well. Having not faced hair loss of this degree since her youth, Bella felt out of her depth. She referred to this experience as her "dark period" and "lost year." Time seemed sped up, as she grappled with what to do. Bella felt she had no choice but to disclose her AA to her boyfriend despite fear of potential rejection. She found his focus on wanting to be with her, rather than on her hair or the lack thereof, was comforting and eased her concern. Bella decided to try a glue-on hair piece, hoping it might provide her an element of normalcy. Eventually choosing to get a wig, Bella had to confront the image of herself with no hair. She came through the other side of her dark period after finding greater comfort with her wig. This comfort allowed her to begin to build a new support network. While Bella started her lost year feeling out of her depth, she left it armed with strategies as well as greater self-knowledge.

Through this time and into the present Bella continues to use strategies to regrow her hair, such as medical and herbal remedies, because she sees the alternative is to accept the permanence of her AA. An ongoing area of difficulty is intimacy with romantic partners. Bella recognizes that she may need to learn to tolerate greater discomfort or ambiguity regarding romantic relationships, but still finds it difficult. Bella continues to experience self-consciousness about people recognizing her AA. She is beginning to want to share more, but the moment of revelation is still frightening enough to hold back. She also continues to have a limited range of experiences as a result of her

AA (e.g., no swimming), and is growing tired of the limitations for herself and others. Bella mentally works through her options for presenting herself to the world (wig, scarf), recognizing that where she is now is a liminal space in which none of her options really “feel like me.”

When reflecting on how she understands her experience of alopecia areata in her life, Bella explains having AA has taught her lessons about priorities. Through being vulnerable and disclosing about her AA, Bella gains deeper friendships. She also finds herself having less judgement for others, making her a “better person.” When thinking about her future, Bella predicts her process of acceptance may need to accelerate. Bella is considering ways to have greater freedom, so she can more fully live her life when she becomes a mom and a wife.

Detailed description. Bella’s description of her first experience with AA exemplifies a change from baseline low awareness of her appearance at that time of her life.

> I was 10, which was 5th grade. I didn't even know it happened really. Being 10, you're not super aware of things. We were in the bathroom combing my hair. I remember looking in the mirror, and at that moment my mom saying something like, “Oh, your hair seems a lot thinner. Have you noticed?" And then me looking in the mirror and being like, "Oh, I didn't even notice." It hadn't really dawned on me. I didn't feel anything. I was like "Oh, okay." Kind of just how kids react to stuff. And she's like, “I think we should go to the doctor.” It's like, “Okay.” And I don't remember having any feelings about anything until I started seeing people. It didn't even register. I don't think I was really looking at myself. You look at yourself and you're like, "Oh okay, that's me I'm in my clothes" and whatever. It was one of those things I was completely oblivious to until somebody pointed it out to me, and then all of the sudden it became a bigger deal.

While previously her appearance was viewed neutrally, it would take on greater significance and becomes “a bigger deal.”

Going to visit doctors for Bella further increased her self-awareness, and she felt the space of their clinics and the way they interacted with her conveyed that something was seriously wrong.

> I just went to my primary doctor at first. I remember them not really knowing, but saying that going to a dermatologist would be probably the way to go. I think we saw just a regular dermatologist first because he was like a creepy man. I just remember him being a weird guy, and he had a weird name too. He confirmed that's what it was, and then he recommended me to a specialist because I was so young and she was the one doing everything with it at that point.
>
> I remember it just being terrifying because I didn't feel like anything was wrong. So then all of the sudden we're seeing several doctors, and they all had funny last names and they were all really serious. They weren't child doctors who kind of play around with you and are really nice. I remember them being really serious. And the specialist had like seven thousand other people in the room with her, because she's a teaching doctor, so I remember that being really intimidating. We went and saw her, and we started developing a plan.
>
> I only went to the doctor if either I was sick or if I had to have some sort of a check-up or shot. So, I think I start realizing that something is wrong with me; I wouldn't be at the doctors if something wasn't wrong with me. And I think that's what's scary. You don't feel sick with alopecia, you're perfectly fine. So then I’m like, “Well somebody is telling me that I'm sick.” And I think that's what's scary. I have asthma too. I think I just equated it to what I experienced in the past. So I think then I started to worry like, “Okay, well what's wrong with me now? What do I have to do now? How is it going to affect me?” With asthma you can't run, you can't do as much physical activity. I'm allergic to a lot of things. It’s like, "Well, what's it going to change? Is this going to impact my ability to do the things I like?”

While at the doctor’s, Bella was internally making sense of what she saw, which seemed worrying. She was no longer treated as a child, further emphasizing that her life had changed.

Bella explains her early experiences of AA felt perceptually different from her previous normal: time seemed on fast forward, she felt she was continuously being observed, and she developed a “hyperawareness.”

> I just remember not really thinking much of it until after I started seeing people. I felt like eyes were on me at all times. I feel like after people started pointing it out in my family then all of a sudden it became a bigger deal to me. I just remember feeling self-conscious - and at 10 you don't even know what that is. And I went on prednisone, so it made me kind of balloon up, so my face was chubbier. I just felt like a completely different person. But that's really all I remember from being a kid was just feeling all of the sudden things just changed overnight. I feel like I was just much more aware of things after that.
>
> I feel like if people stare at me too long they're figuring out that something is different about me. And all I've ever really wanted is to just kind of blend in and fit in.
>
> What I mean by changing overnight was it was I didn't realize it, and it went from me not noticing anything to me being self-conscious and noticing *everything*. In that time span, whatever that may have been between my mom telling me or bringing it up and then going to those doctor visits, the instant people started whispering and saying things, then all of a sudden I was hyperaware. And I guess that was my overnight, because it all happened so quickly. I feel like it was one minute she was talking to me in the bathroom and I was at all these doctors, and then it was just a flood. It all just seemed to kind of happen fast. All of a sudden I was just hyperaware of everything. I didn't feel like a little kid anymore. All of the sudden I was just nervous all the time. It wasn't fun. I guess there isn't much to it besides the fact that all of the sudden I didn't notice and then I was hyperaware.

The attention engendered a reflexive self-consciousness; an awareness of her difference. It was as if Bella’s noticing others reactions to her AA turned on a switch that rapidly advanced her from a state of childlike innocence and freedom to having an adult-like burden of constant awareness and concern.

Bella’s experience of awareness and concern happened in the context of her encountering unkind reactions from her peers, which added to her feeling different.

> Girls are mean. I remember being on a field trip and girls were being really mean about it. Asking, "What's your deal? What's wrong with you?" I don't remember what specifically my so called friends would ask me. But I know it was always in a rude way. It was never out of concern or worry, it was always in a snotty tone. And it was almost like those feelings of being bullied in first grade all over again. It didn't feel good. I swear I blocked a lot of that out, because I really don't have strong memories of feelings until high school. I remember, I think I just felt just completely out of my element. I felt like I was going through the motions. Still hanging out with people and being friends with them, but not feeling like I fit in. That was a big thing I felt, in 5th and 6th grade, that I just didn't fit. I just never found a niche, and I think I just had a lot going on in my mind – just thinking that I'm not the same as these people. I remember still being part of the crowd but not really feeling like I fit in with the crowd. I just remember not wanting to do as much with those girls.

Publicly, Bella put on the persona that nothing had changed, but internally she hid feeling that she was different. She was unable to escape her peers at school, so she longed for the escape of summer.

> I just remember wanting the school year to be over. I remember being really excited going into the school year because I got in the class I wanted, I got the teacher I wanted – but then it all kind of went downhill. I just remember wanting school to be over because then I don't have to see anybody if I don't want to. That's the big thing I remember; just being ready for school to be over. I was never that kid. I never wanted to start school, but I didn't necessarily want it to end. I always had a good time there. So it was abnormal that I felt ready for this to be done.

Bella reflects that her experience with AA changed her experience of school; it was no longer a place she felt comfortable. Bella and her family searched for options to bring her relief.

In their search for options, an ill-fitting wig leaves Bella feeling that wigs are dangerous for their potential to make her even more different from who she feels she is, when all she wanted was to still look “like me.”

> I went to try on wigs when I was 10. Because alopecia wasn't such a prevalent thing, they didn't have kid wigs at that point. I had to try on an adult wig, and I just started bawling my eyes out. I have blonde hair, but they tried to put me in a bleach blonde hair wig, because I think it was the smallest one they had or something. I don't remember the reasoning, but I just remember bawling. And being like, “This isn't right.” At least whatever hair I have left still looked like me. I've always been tiny, and a giant crazy big hair wig just looked completely not realistic, and not what I wanted to look like at 10, 11 years old. That wasn’t traumatizing, but something that sticks in your mind. I have a wig now and I remember I never wanted one because of that experience. I feel like I've always had posttraumatic stress; I always refer to it as that.

Bella explains that her experience with the wig as a child still impacts her today.

> When I'm obsessing about something and people are like, "You look fine." I'm like, “I'm just having weird anxiety. I'm having weird posttraumatic stress. I just can't function right now. You have to bear with me. I'm having one of those days.” So every time I get a new wig I'm like, “Does it look too big? Does it look unrealistic?” I need it to look as normal and real as possible. I have a friend who is a hairstylist who is like, “If it was me I would have a pink wig, and a curly wig.” I'm like, “Okay, you say that now.” But if you're sitting there and losing your hair for god-knows what reason, and you're trying on all these wigs – it’s like, I just want to look like myself. I don't want to look like some crazy person. I'd like to just be one of the crowd. That was scary. And just completely off-putting, because it's something that no kid should ever have to do that.

Bella was threatened by the trauma of potentially further losing the ability to look on the outside like the person she felt she was. She still feels haunted by that strange and scary image today.

Even though wigs did not provide relief, Bella soon found respite when her hair regrew. She explains:

> And then the prednisone, all the stuff that they prescribed really helped because my hair started coming back. It came back rather quickly. By 6th grade I think I had most of it back, and I didn't have an issue then for another couple years. So luckily in middle school I got a fresh start. That was nice because I went back to school. I don't remember having any feelings about being nervous about it. I think by that point it was all back,

> for the most part, looking more normal. And, it was new people, new stuff, so that all kind of went away. I still would visit the local doctor, and I think I would get spots from time to time, but I think they were pretty manageable.

Bella was largely able to move on from the initial experience. Still, some underlying fears persisted, developing into somewhat of an unconscious reflex.

> I think, 6th and 7th grade were normal. I don't have like any big highlights. But as far back as I can remember, whenever anybody even remotely touches my hair I tense up. I do it now and I've done it since then, because I feel like I've always been hiding something. I think even in 6th and 7th grade I still had spots. I'd get the little round circles here and there; it just wasn't as bad as it was in 5th grade. I think I just didn't want anybody to know. As far as I can remember I would always get really tense if someone touches anywhere near my head. I get a little bit weary of, "Okay what are you going to do now?" Because I don't want you to do anything else. This is about as far as this is going to go before I run screaming.
>
> Now, with a wig, I don't want you to feel that my head doesn't feel like a normal head. It doesn't feel too bad. People have touched it and haven't said anything. But, I'm worried about it for the next probably 30 minutes after you touched my head. Even when I had no alopecia, I think it's been ingrained in me. I don't want anybody to touch my head. It's one of those psychological things. If you touch my head I'm going to get a little anxious. My gut instinct is to tense up and to get almost like, "What are you doing?"

Bella continued to conceal and keep her AA, now relatively minimal, hidden from others.

The AA eventually returned, and Bella found herself helpless to hide her AA. Self-conscious and uncomfortable, she struggled with looking different despite her best efforts.

> Eighth grade was the next time, so about 3 years later from the initial. It started in the front area, which is a super obvious spot. It’s unfortunate because you can't hide that by any means. And, in 8th grade is when I started liking boys more. I wanted to look nice. I was back to being self-conscious because I went back on prednisone, so I have pictures of the fat face happening again, and it's hard because you can't hide any of that. And

> being on the top, you can't buy anything that really solves that problem. Besides a whole wig, which I swore I would never do again after my traumatic experience as a 10-year-old. So there's nothing I could do but let it be. And again, it was the whispers and the questions and the people asking my friends. There was a few accusatory, "What's going on?" type questions, but not so much in 8th grade. It was more behind your back talking then. More the gossip, "Does she have cancer?" Because that's always the go-to. And you feel fine, so it's just hard to hear because you're trying to look nice.

Bella explains that she again feels distinctly different from her peers because of the AA. Unable to hide the AA, Bella used the strategies she felt were available: she engaged less in life, and avoided talking about what was happening or how she was feeling.

> I was just uncomfortable. Again, I felt like I was behind and not totally in the group because I was too nervous to go outside of whatever comfort zone I had kind of created for myself. It made more introverted, and I'm not an introverted person – I'm very extroverted. But when it came to when I have flare-ups, I just wouldn't want to do a whole lot. I found myself turning down activities because I didn't want to be put in an awkward situation where I was going to feel really uncomfortable. I feel like it stopped me from doing things with friends just because I didn't want to be put in a weird position. If it rained it made me nervous because my hair was so thin. It takes out pool parties too.
>
> Being in 8th grade was even worse because you don't know who you are period at that age. Alopecia just added one more layer to it. One more thing to maneuver and figure out is where does this fit. Which is why I kept the secret because when you're that age nobody has anything. And if they do, they're not telling anybody. Everybody was talking about being depressed, and I feel like I was depressed too. But everybody thought cutting was the thing to do to show that they have all these emotions, and I was hiding my emotions. I felt like I was the opposite. I'm not putting it all out there. I want to keep all of that to myself. I just kind of put on a happy face and pretended like I was the normal one. I was trying to “fake it ‘til I make it,” and I felt like I was trying to overcompensate for everybody's kind of outward sadness. I kept all mine inside and kept it to myself, because hiding it has always been easier.

Hiding the feelings about AA was a safer alternative to being vulnerable. Seeing her friends expressing their emotions, however, led to Bella questioning some dark thoughts.

> I feel like you can't participate in everything, so that just makes you feel like even more of an outsider. Even more of a loner. And that's the thing, I feel like everybody in middle school is depressed. Alopecia made it harder because when I looked at myself I was like, “I don't even look good. I can't do what everybody else is doing, I can't experiment the way everybody else is experimenting.” So I felt more lonely. It's scary because, everybody has those thoughts. “It would just be easier if I didn't have this, I wasn't here, whatever.” It's like, well if they're sad and depressed, I've got real problems. They don't have any problems. I have a real thing, should I be thinking this? In my mind, I was the only one that had something real going on. I think it's scary because it's like, should I be having these thoughts?

Despite the difficulties at school and with friends, Bella found support and safety – her “sanctuary” – at home with her family. She explains:

> Luckily I have a good family, and they've always kept me busy. That was my outlet to find somewhere, a safe place. I've always been super close to my family and they've never treated me any differently. It's just, that's kind of my, sanctuary-type thing.

The important aspect of this support is not being treated differently. This was important, because her parents were the only people with whom she ever talked about her AA.

> My family is always afraid to talk to me about it because I didn't want to talk about it when I was little. I didn't get it, so it was hard. Everybody knew, it was like an unspoken thing. So everybody knew about it and it was only really my parents I would really talk to about it. Especially because people would tease me when I was in fifth grade, I just didn't talk about it with friends. Then it went away, and I'm like, “What's the point of talking about it if it's not a thing.” But then it got worse again. I had a good group of friends at that point, but I still never felt comfortable telling them what it was. Again it was like a secret; it was an unspoken thing. They're not blind, they knew it was there, they just never said anything about it.

For most relationships, even though the AA was visible, it was never openly acknowledged.

Bella appreciated when friends allowed her to keep her secret. She describes an example in which a friend gives her an “out.”

> Another key thing I remember was in eighth grade, with that spot and it was thinner. I was riding the school bus with one of my really good friends and she told me "Somebody today asked me if you have cancer." And of course, I panicked. My immediate reaction is to tense up and panic, to kind of stiffen up and see what else she had to say. She's like, "Do you think it's just because you're so skinny?" I've always been a very slight person, even smaller back then. I was thinking, this is why you are one of my best friends. She clearly knew why they asked, and she was giving me an out, which I thought was really nice. Because we still never talked about it. I kind of brushed it off and said, “I don't know” or whatever. I tried to play it off.

Bella shares more about her experience of keeping her secret of AA.

> Keeping secrets, as much as you think they're kind of fun, they're really not. Keeping a secret, especially from best friends, is hard too. You're kind of living some sort of lie. It's not a creepy lie, but it's a lie nonetheless. Making up excuses and lying about it’s so much easier than telling you that I have alopecia. It's an insecurity, and it just makes me more vulnerable. I absolutely hate that. I hate when people know your Achilles heel, and alopecia is mine super hardcore.

For Bella, not telling someone about AA is safer because it prevents her from having to feel vulnerable. With her friend, she was saved from being in that vulnerable space.

Bella explains that her AA changed in high school, and that not hiding or keeping a secret allowed her to feel safer trying new hairstyles and sharing about her AA with friends.

> I had a hairpiece in 9th grade – it only covered half my head, like mid-part I had a clip-in. And by the end of 9th grade, I had enough hair to get hair extensions in the back. My high school years were probably my best years because I had either my own hair or I had extensions, which are pretty much old news now. And I could explain them, it wasn't a secret, it wasn't like a hidden thing. Like if I said I had extensions people were like, "Oh, okay." So high school was kind of my growth period, I feel like I actually got to step out of my comfort zone a little bit more because I wasn't hiding a whole lot. There was a few things to hide but nothing major. It was things like in the back area that nobody would have known about; easy to

> hide, easy to maneuver, ponytails and all of that stuff. So I feel like I really started to accept it more and realize that this is what it is and I have it. It was good to finally feel comfortable enough to play around with my hair, and to work on trying to hide it. I finally started feeling more comfortable with the actual disease, knowing that my hair wasn't going to fall out just because I put it in a ponytail. I started tugging on it and moving it around.
>
> I was more willing to start sharing with people. I started having real friendships, people that I trusted. People who I knew weren't going to run and tell somebody else that I had it. It was finally people in my life that were there to stay. There to understand. Not pity you, but understand and get it. I did start to let people in a little bit more. Little by little I've grown so at least at that point a few people knew.
>
> It felt good to finally tell somebody. I think I actually realized this is here to stay, and I have to figure it out instead of trying to hide it so much. I still wasn't shouting it from the rooftops, but I was kind of adapting and changing more than I would let myself before because I just kept thinking it would go away and just stop happening. And I think in high school I was growing enough and having enough support from people and friends, and people I actually liked. I feel like I was kind of growing into myself. So I feel like that’s helpful.
>
> I had finally started telling friends in high school. I had a best friend who I sat down and told. We shared a locker, so I remember showing up finally to school and being like, "Does it look okay?" And I finally had someone I could ask, so that was one big thing going back to being a teenager. I finally started opening up to a friend or two in high school. By the end of high school I think about 5 people, besides family members, that I had openly told about it and told them what it was.

Bella told others about her AA, and had experiences contrary to feared expectations. She gained additional support by sharing with trusted people. Facing the constancy of her AA opened her up to living life more broadly, yet she was still hoping for it to go away.

> I think in high school, as much as I was accepting it, there's always hope that it's going to go away. Especially when it was so good in high school. I thought maybe if I just embraced it, it will just stop. If you keep that positive attitude, maybe it will just go away.

While it had become easier to conceal her AA, it remained a source of anxiety for

Bella. She shared:

> In high school especially, my anxiety – I can feel it. I became almost OCD about my hair, because I still had my own hair at that point but I was hiding stuff. So my mom wrote me a note to keep in my car that excused me for being late if I was having a bad hair day where I was obsessing over my hair or my hairstyle. That note is like a long running joke in my family because if I used it she would write me another one. I would keep it in my glove compartment and give it to whatever my first hour teacher was because it became a huge habit. I would curl my hair and I wouldn't like it, and I would have to re-straighten it. I would have to take a shower again. I'd have to re-do everything I had done in the morning, and then be late to school.

Bella describes an overwhelming concern to make sure the spots were appropriately covered.

After high school, Bella experienced a dramatic change in her AA that resulted in a major emotional change as well.

> College was a big deal. My dark year was in college where everything kind of went downhill. It was such a weird road, because it kind of went super-fast. The hair loss and just the time in general. I call it my lost year, because we didn't know what to do. I hadn't researched anything. I always said I was never going to do a wig. So I had to do a lot of figuring out what I was comfortable with because it was coming out so much more than it had. It was like it was when I was younger, but back then I wasn't looking in mirrors, wasn't caring a whole lot what I looked like. Now once I got older, the more and more I cared about my appearance. So it was challenging because I had no clue where to start. And all I wanted to do was pretty much hide for however long it took for it to grow back, or to figure out what to do.

Having not faced hair loss of this degree since her youth, Bella felt out of her depth. Time seemed sped up, as she grappled with what to do.

Bella came to a solution that she felt would provide her an element of normalcy, something she desperately yearned for.

> I ended up finding a hair restoration place. I had never not been able to go

> swimming or go in water or do anything like that. I don't even remember why I didn't want a wig. Looking back I kind of blame the fact that I don't have hair still on that whole experience, because what I found was something you glue on. You shave your head and you glue it on because you could go in water, you could take normal showers, because I wanted to be as normal as possible. I almost wanted something that you couldn't take off. And I mean, looking back I appreciate so much being able to take it off now. But I didn't know that at the time. I thought I just wanted it to be as normal as possible and normal people don't take their hair off at the end of the day. My parents and I did research and we found this place that did these hair treatments. So you go and you have a consultation and you figure out what you want. And it takes like a certain amount of time to produce it and get it made and shipped and all that. It was luckily I waited until summer time, so you're not seeing as many people. I had decided this was what I was going to do. I was planning on getting it in a certain amount of time, and it didn't happen.

Bella longed for an option that would mean she would not have to face the image of herself without hair; perhaps, similar to the experience with the wig in her childhood, not wanting to look like someone other than who she feels she is. Not wanting to lose her freedom to swim.

Bella, not having disclosed about her AA to many people, escaped to where she might take a reprieve while she further determined what to do.

> It was falling out so rapidly, I decided to get rid of the hair early. And I went and actually lived in a different state for 2 weeks, because it was people didn't know. Not many of my friends knew, my boyfriend didn't know. So that was hard, which I wish I would have done differently now.
>
> I was gone there for 2 weeks. While I was gone, I was researching herbal treatments and things you could do to grow it back. My cousin, who I was staying with at the time, took me to this herbal store. I guess I technically have met somebody with alopecia because he had it. We walked in and he had no eyelashes, no eyebrows, and no hair. We said we were buying it for alopecia and he was like, "You probably just want to come to terms with the fact that your hair is never coming back." And I was like, "Okay. You're really cool. Thank you so much. [Sarcasm] I'm pretty much going through the hardest time ever.” My cousin was dumbfounded and felt terrible. I kind of held it together until I got home, and then broke down

> and called my mom. My mom almost drove there because she felt so bad. So it wasn't a fun time necessarily.

While Bella was looking for a solution, she found the last thing she wanted to hear – that her AA might be permanent. For it to be permanent would mean the potential for her normalcy, for her image of herself to return, would be impossible.

Prior to her leaving, Bella had made plans for a special trip with her boyfriend. With her hair loss continuing and her new hair piece not having arrived, she felt no choice but to disclose her AA despite fear of potential rejection.

> It was right before the 4th of July, and we had plans to go out of town. My boyfriend was supposed to come along. My hair piece still wasn't ready, so I had to tell him about it. I had come home a week before and stayed with my sister. I said I was still gone. I had to come home, so I called him, told him everything over the phone. And he was like, "So wait a minute. You're here right now? You're at your house? I can come and see you?" And I was like, "Yeah, but I don't look the same." And, he was like, "Well I don't care." It had been a hard few weeks because I shaved my head, was wearing scarves, had never experienced that before. So telling my boyfriend at the time, and then telling him that I've been pretty much lying to him for a month. And all he wanted to do was come and see me, and he could have cared less. Telling him was probably one of the hardest things ever. But I will always remember the fact that he was like, "Wait a minute, so you're here? I can literally come and you'll be there?" I remember opening the door, and it was terrifying. I was shaking the entire phone conversation and the entire wait for him to come over. When he got there he was like, "You look badass!" I was wearing like a bandana kind of a thing. And that was the first person that I told that I was like, "Okay good." Because you just don't feel as cute when you don't have any hair, at least right away. You get used to it, but it was still such a shock looking in the mirror and having to realize that that's me. Then pretty much probably the whole time we hung out that first time was probably the weirdest feeling. The weirdest feeling because that's somebody who could have left. Your girlfriends aren't going to leave you, but a significant other is completely different. But he was really good.

Bella found his focus on wanting to be with her, rather than on her hair or the lack thereof, was comforting and eased her concern. Her statement that looking in the mirror and facing her image was a “shock” perhaps relates to her wanting to keep her image “as normal as possible.”

Eventually Bella’s hair piece arrived, but she found it did not provide the normalcy she was hoping for.

> I ended up finally getting that hair piece thing. It was awful. I hated it. I got it I think in July. I had it July through October, and I would get a new system like once a month. Again, this was my lost year so I don't really remember, it's all kind of fuzzy. But I think I had it from like July to October, November maybe. And every time I'd get a new one it was never the same. They put it on and then it was stuck, so if they didn't put it on exactly right you were stuck with that for a month. And it just never felt right. I wanted it to be this grand solution, like it was going to solve all my problems. It just created more. And I still wasn't used to looking different. As much as it looked like me, it still didn't look like me. So that was hard. On top of that, it was a really hard school year too. It was probably my hardest semester I've ever had too. So on top of all of the depression and anxiety, and just not feeling like myself, I also was struggling to get by with school and meeting new people. I was very much introverted that first semester, which was really hard because nothing about myself felt like me. That had never been the case before. I had always been able to overcome things. I just couldn’t overcome this, which was hard.

Bella’s efforts to deny her hair loss created more problems than relief. The experience was difficult for her family as well, who worked with her to find an alternative option.

> My mom hated picking up the phone those first few months of school because I would call her and I was miserable. The hair wasn't right. She was like terrified to answer every phone call that she got from me. She knew something needed to change. My parents actually went to the place where I went and tried on wigs when I was younger. When I starting to lose my hair in my freshman year of college, we went back to that place. My parents talked me into going to some kind of fashion show the wig salon was putting on. So we went to that, again it was probably like October, November. And, the wig I have on now was one of the ones they were modeling, and it looked so realistic. It's like really good human hair, and you could pick the color. They were dyed, they were highlighted, they were everything, all the words that I was used to hearing when I had my own hair. And they just looked great. You could take them on and off, but they had grippers on them so they stayed tight. They also talked about tape

> and stuff, but, we were there and it just seemed like a better option. So they found this fashion show, we went to it, and we found these. I ended up getting a stock one within the next week of that. I got my hair piece removed, and went right into this style of wig. It was a stock piece so it didn't fit me just right, but at that point anything was better than what I had been doing

With the wig, Bella had to confront the image of herself with no hair. But doing so opened her up to greater comfort.

> I had to get used to having no hair and looking at it in the mirror. I was hiding that. I didn't want to look at myself with no hair. So the glue-on just seemed like a normal thing because I don't want to see, no one wants to see a bald head. I had assumed no one wanted to see that. So with this, I had to get used to looking in the mirror and knowing that's what I look like without the wig on. I just have to get over that. So, it was definitely a learning curve. I had that stock piece for about a year, nine months to a year. And then I finally got a mold of my head and got one that fit me better. And they've just gotten better and better as I've gotten older and figured out what I want, and what I want to look like. They’ve stayed similar but been able to kind of change a little bit here and there, just to make them better and better, which has been really nice.

Switching to a wig offered better concealment of her AA publicly, but it forced her to begin to come to terms privately with her hairlessness.

> That year was definitely hard, because it was getting used to so many different things all within a year timeframe before I felt comfortable. I think feeling comfortable happened once I got the new wig, which was really form fitting and it was less work. I have a really small head. So, the one that I got was too big, and had to be taped and all this finagling, which wasn't a lot of fun. They have just gotten easier and better and that's just made the whole process a whole lot easier to forget about, so that's why there are days now where I don't even think about it until it's like, "Oh, I get to take this off now" and be actually comfortable. So it's just improved from there on out, but that was just definitely kind of my dark year. I can dig myself into a hole pretty quickly, and that hole kind of lasted for a good probably 6 months before I was able to start digging myself out and feel like I look remotely human or attractive or like myself.

Bella describes more about how this dark period manifested for her emotionally.

> I for sure wasn’t going out as much, doing as much. I hate how much it made me not meet people and do stuff. It really held me back that year, which was hard because my freshman year I ended up with a lot of my high school friends so I didn't make a lot freshman year either. So sophomore year was supposed to be my fresh start, to meet a lot of college friends and put myself out there and really get into the swing of college life. And it just didn't happen, which made everything that much harder because I didn't have a very good support system. A lot of my high school friends, a couple of them ended up going to different schools or finding their majors and being too busy. I feel like the bottom kind of dropped out where I didn't have the support anymore. I definitely went home a lot more. I just feel like I was really closed off, like I didn't want to do anything and I just wanted to hide as much as possible because it just seemed easier. And that's just not like me, I'm very outgoing and I want to be doing stuff. I just felt a completely different version. It was definitely the closest thing to depression that I've ever experienced because I thought everything was just too much work. Too much work and that life just might be easier if I didn't have to do any of it.
>
> Definitely sadness and loneliness and just kind of broken. I just didn't feel remotely like myself. And I mean there were times I put on a happy face, but for the most part I felt outside of my body. Everything that I was doing, I'm like, this is just not me. I think I could have been fine just sitting in my apartment probably all day everyday just kind of shutting out the entire world. I didn't want to be around anybody because I felt like I was just such a downer. All I wanted to do was complain and talk about how terrible life was. This was my worst nightmare basically. Because I didn't have a great support system of friends, I didn't have anybody to kind of pump me up and remind me that I'm still cool and that I'm still fun and can do stuff and they want to be around me. I kind of lost all of that within the same timeframe.

Bella came through the other side after finding greater comfort with her wig. This comfort allowed her to begin to build a new support network.

> My roommate – this random girl that I ended up with – we met freshman year, before the school year ended. She was very outgoing at the time and so was I. We both had rough summers. When she started school she was at a low point too and so was I. When school started we barely talked to each other. We did our own thing, we were both secluded and in our own holes. Then all of the sudden after I got this new hair, it was after Christmas vacation because I think I got it right before. When we had our winter break we rejuvenated over that break. I was getting more used to the new

> hair and everything. It was kind of a fresh start coming into the second semester. I think we were both in better places. Then after that we started hanging out more. I think it was a good growth, I really got to know myself and what I need in those 2 years, like the dark year and then kind of coming out of it. I really figured out who I was as a person, I did a lot of reflecting and thinking and overthinking and too much thinking. I feel like I genuinely figured out what I need as a person – what gets me out of funks and what puts me in them. I just feel like I've gotten better and better at finding good people to add to my group ever since those couple years.

While Bella started her lost year feeling out of her depth, she left it armed with strategies as well as self-knowledge.

Bella continued to use strategies to regrow her hair for some time, including medical and herbal remedies.

> I've done the shots, the shampoo, the creams, prednisone, pretty much everything you can do. Because I did say at one point that I'd never do shots, and I did shots for a long time. It started as patches, because they were saying that would be the quick fix. So they started doing it when I had patches but then the patches would get bigger and I kept doing them until the patches got quite large. So I did that for a long time because nothing else was really working. I did that for probably longer than I should have because I think at one point I was getting like 100 shots. And then I think I finally was like, I can't do it anymore.
>
> My hair lady ended up in my neighborhood. She was at this street fair, and my parents found her when I was miserable. There's this whole regimen she does, and I would go and see her once a week. Now that I've started growing hair, it lessened to once every 2 weeks. It's not pills, and it's not anything you have to constantly take. It's more like a supplement that you're doing in addition to this treatment that she does. And it's working. It was super random that we just happened to find her, I swear she was put there just for me. That's what I like to think anyway. And, she's the only person that's gotten me to have any progress that didn't involve some sort of pill, because I just hated all that stuff. It got to be just too messy and too much. And a lot, time, when you're a kid you can do all that, but having a job and having a life, I couldn't' go to the doctor that often. So finding her was great because otherwise I think I would have had to just come to terms with the fact that I may never have anything. And I'm not there yet. I'm not ready to embrace nothing.

Bella continues treatment because she sees the alternative is to accept the permanence of her AA.

Bella explains an area that has been difficult for her is intimacy with romantic partners. Getting to feel comfortable sharing about her AA is a challenge. Her one exception is her boyfriend from the “lost year.”

> Dating has always been hard for me. As I said my boyfriend who I told has been in and out of my life. I haven't told any other guys before. I still don't know if I keep him around as my safety net because I'm comfortable and I don't want to tell anybody else, or if we're actually meant to be together. That's something that I struggle with now. It's still hard to feel attractive. I don’t know, is someone going to run away once they find out? I've dated casually, but it's never gotten to the point where I've wanted or needed to tell anybody else. So he's literally the only boy in my life that knows besides family members. I've never told any other guy. I've always been tempted to, especially when I was dating. I've had other guy friends that I've wanted to be like, "Hey would this freak you out?" But a lot of my guy friends are gossipy, and again I never like the fact of wondering, “Are you going to go tell the entire world?” There’s been a few other people, but again there's never a good time to bring it up. And I chicken out. I just don't know how guys are going to react. I've always been a girl who hangs out with a bunch of guys, and you just hear guys hate girls with short hair. What do they think of girls with no hair? I go to the extreme.
>
> My ex-boyfriend could have cared less. But we had already been dating for a year, and we had been friends for 2 years before that. He knew me really well. So obviously he’s not going to care because he actually loves me and knows me as a whole human. But telling somebody that I’ve only been dating for a few months that doesn't know my whole story, hasn't grown up with me, still freaks me out. Because I feel like it's a big deal. It’s not that they're not going to think I'm still a cool person, but are they going to want to go to bed with somebody who doesn't have hair every night? And wake up every morning? I want to be able to walk around my house without any hair on until I literally need to leave the house. Are they going to be able to look at me the same way? If it's the right person, I know that they would. But it's hard to get to that point for me because I always have a wall up until they know. It would be easier to tell them right off the bat, but I don't want that to be something that makes them run away right off the bat either.

> So that’s probably the biggest thing I struggle with, especially because my ex does seem to circle me. We're trying to figure out if we have a future together, and I struggle figuring out, do I think you're the one because I'm really comfortable with you and you already know? Or is this a real, legit, we could spend forever together? So, I'm terrible with relationships. Those kind of relationships.

Bella’s concern for rejection is relatively untested, with the exception of her ex, and she is starting to feel more pressure to make a decision.

> That's my biggest frustration with this, because I want to find the right person for the right reason. It's gotten harder the older I've gotten because you're expected to get married sometime and you need to have babies, women have to have babies within a certain window of time. So your clock starts ticking right around my age that I am now, so it's become even more pressure. So that's what makes it hard is I don't want to settle, so that's where my struggle is with my ex-boyfriend is. I don't want to make a decision on my future just because I'm comfortable with him. So it's hard because there is like a lot of love there, but is there something more out there and I just don't want to figure it out? So that's what's hard is getting out of that comfort zone because this whole disease makes me uncomfortable. So that's what's hard is being comfortable being uncomfortable, if that makes sense. Because I feel like I've put myself in a lot of uncomfortable situations and with relationships and guys, that's one thing that I’m not comfortable being uncomfortable with.

Bella recognizes that she may need to learn to tolerate greater discomfort or ambiguity regarding romantic relationships, but still finds it difficult.

Bella talked about some additional aspects of her current, everyday life. One situation that continues to come up for her is self-consciousness about people recognizing her AA.

> I don't have eyelashes right now. I feel like if people stare at my eyes too long I have to look away. Because I don't want you to see; I don't want you to figure that out. I even did that as a kid. You just feel like people are watching you.
>
> So the self-conscious is mental. The older I get the more people tell me,

> “You know it's in your head.” It's like, “Well I know it's in my head, but it *feels* like it's not.” Because you have a body sensation, like I can tell when I'm getting anxious. And I can tell when I'm getting nervous. And it's not around everybody; it's not like day-to-day. If I come into a coffee shop and get coffee, I'm not worried about it. But it's when people that you know really well are staring at you and you're like, I kind of want to tell you. But I also don't really want to tell you. Because I feel like you're figuring it out. But I also don't want to bring it up because I don't want to rock the boat and I don't want it to be a negative experience, even though at this point in my life I know it won't be. But I feel like I've been ingrained to think it's going to be a negative experience.

Bella is not overwhelmed by concern about people recognizing her AA in all situations. She is beginning to want to share more, but the moment of revelation is still frightening enough to hold back.

Bella explained part of the current difficulty with AA is ongoing fear and concern about others’ reactions if she were to tell them, despite a growing desire to open the circle of people who know about her AA.

> Once you start experiencing people talking about you behind your back, and people asking a lot of questions. That's what I always equate having to tell somebody to. I always think they're going to react a stuck up way. Kind of like, 'What's wrong with you?" Because that's how I first was exposed to people knowing, or people asking, or people asking in an almost accusatory, judgmental way. So I feel like if people stare at me too long they're figuring out that something is different about me. And all I've ever really wanted is to just kind of blend in. And fit in.
>
> Now there's been a few friends that I've told that I thought were figuring it out, and they're like, “I had no idea. I had zero idea.” And then I've had friends that have been like, “I've wondered,” but not a big deal. I always feel like people are trying to figure it out. And I, my biggest thing is I always associate it with being a negative experience, but everybody I've told it's made our friendships stronger and people understand me a little bit better once they know. But I think it was ingrained in me so young to associate it as negative. And that's why whenever I end up telling people they're like, "I thought you were dying." Because I build it up so much in my mind. So when I tell them, they're like, "Oh, my gosh, that's it?" And, I'm like, "Yeah." And they're like, "Well you're making it seem like a big

> deal." And I'm like, "Well it’s a big deal to me!" And they're like, "Well no, I get it. But I'm just glad you're not dying." And then I have to explain to them. I do refer to it as posttraumatic stress because I'm like that's all I think of. “While I'm telling you, I keep expecting you to look horrified and be disgusted that this is a thing and I have it. And this is a big deal.”

Bella explains the fear of a judgmental reaction is difficult to shake despite the positive reactions she’s experienced.

> I tell everybody I'm an open book, but that's like the one chapter that’s on lock-down and you have to be super special to get that. And most of the people that I've told are my best friends, my family. I have two friends that I'm not friends with anymore who know, and it's a big deal. [emphasized] It's not just anybody. When I'm comfortable enough to tell you, unless you somehow figure it out in some weird way, if I'm the one telling you, you're an important person in my life. Those are deep relationships to me. So those two girls who know – who are just out there now that I'm not friends with anymore – I get really upset about it. Because it's such a big deal. It’s the thing that nobody knows, the thing that makes me who I am that I like to keep to myself.

Bella feels entrusting her secret to others is so important that she is hurt by people knowing no longer being in her life.

Bella explained another aspect of her current life is longing for some of the “normal” experiences that come along with having hair and eyelashes.

> It's so petty, but it's like people talk about makeup. People talk about hair. And I'm like, I don't do a whole lot. Because I just don't have eyelashes, and I can't do anything with my hair. I can, but I don't. So it's those normal girl things. Some of it's nice; it's nice not having to shave every-other-day anymore. But it also sucks because you just don't feel like you're doing what everybody else is doing. Luckily I've had the ups and downs. I've experienced them so I can participate in the conversations, which is helpful when I'm keeping it from somebody. I can participate and I know what it feels like to be normal, relatively so. And I think that's what bums me out is when I have been normal, to an extent, and flip-flopping back and forth is always what's hard. You just don't feel like everybody else. You don't have those same experiences. When I'm hot I can't throw my hair up in a ponytail. I can't change my hair color every other day. I can't try cute new hair styles. It's just like those little, stupid things. And if I got

> thrown into a pool, I would probably have a heart attack. Other people don't think like that. I've been with my mom and it starts raining, she's like, “Gasp! Are you okay?" And it's like, I'm fine. Now I'm fine. I just feel like people have to tip toe around me about certain things, and that's not normal. People don't usually tip toe around people. It's just like, little stupid things. I just feel like people have to be careful.

Bella dislikes that parts of her new life are not “normal” – the things she does or does not do, feels or does not feel, and the way others recognize her sensitivities.

Bella also continues to have a limited range of experiences as a result of her AA, and is growing tired of the limitations for herself and others.

> It's like, my friend not being able to go snorkeling. A *normal* person could scuba dive. I can't. I always say I can't – and I could – but I'm not comfortable with it.
>
> I think I also hold people back a little bit. Like my friend and I just went on vacation. I don't do snorkeling and that sort of thing, and her friends were like, "Oh are you going to do this?" And she's like, "Well no my friend's not a big fan of the ocean." It just *bums me out* that I hold her back from doing something. I'm like, "You can do it! I want you to do it!" So I think I also worry about telling people because I don't want to start using this as an excuse. Because at least when people don't know I can still either push myself or remove myself from a situation that I'm not comfortable with, and they can still do what they want to do. I feel like once people know, I start relying on it as a crutch. As an excuse. Where it's like, "Well I don't want to do that because of this." Where until they know that I either can separate myself, or just push myself to do it and be comfortable with it.

Bella sees having to push beyond discomfort is one of the benefits of not telling others.

> One of my boyfriends knew about it. And I feel like once he knew, I would use it as an excuse. I'm like, "Well I'm having a really hard week. This is why I'm acting like this." It was a good thing, it was the truth, but I just want to be carefree. I don't want to bring in all the crap that I feel about this. I want to tell you so you understand why I'm acting like this, but at the same time I wish I could just get over it. And that's what I do with a lot of the people that don't know; I have to push that anxiety aside and I have to keep going. I don't want them all to know, so I have to put on a happy face. You know, fake it until you make it. I kind of like that,

> and I think that's part of the reason why I still have such a hard time telling people. I almost kind of like when people don't know because then I can't use that. I like talking about it. It makes me feel better. But at the same time, I also like forgetting about it. With the people that don't know, I can forget about it to an extent. I still get anxious if someone touches my head; I freeze up. But at least I have to move forward. I can't dwell on it, and let it marinate and have a big long conversation about it. It's kind of a twisted thing. It's like I want everybody to know, but at the same time I almost like the freedom of not everybody knowing so I have to keep going forward. I can't curl up in a ball every time something happens. I have to keep moving.

Bella suggests that the pressure to play along so others do not find out about her AA can be positive because it brings about extra perseverance, and keeps her from dwelling on negative emotions about her AA.

Bella described a new experience for her has been attending support group meetings, which cause her to internally reflect more upon her own experience and how she wants to be with her AA.

> I started going to these support group meetings. It just makes you think, because people are there in different stages of acceptance or whatever you want to call it. So I find myself reflecting on my stuff after I've been to one of those meetings. Kind of comparing stories or thinking about, "Could I be that person who just walks out one day with nothing on?" Or, those kind of things. It's definitely when you hear other people's stories you start comparing. It's nice to hear other people's stories. And to think, "Oh, mine hasn't been that hard." Or, "Oh, I wonder if I'll ever get to that point."

Bella is being exposed to different ideas about living with AA through the support group, and is finding some perspective on her experience through hearing about the experiences of others.

For Bella, another aspect of her current life with AA is a growing sense of the longevity of her AA, and a questioning about whether to change her approach.

> It's still scary. I know I'm going to have it forever, as much as I'm hopeful that I have half a head of hair right now and thinking, “Man, it would be really cool if I could put my hair in a ponytail again.” It's still scary to know that I have it forever. It's kind of a weird thing to realize because it's like, “Well what do you do with that now? Do I tell everybody?” It's an unknown thing. It's like, I told this best friend but I didn't tell that best friend. It's like, do I tell them at this point or just let it be? It's a weird thing to realize. Because I have asthma, I know what it's like living with something. But I feel like this is so different because it's out for everybody to see.
>
> And you're either covering it up or you're on display, which is scary to me - I never liked being the center of attention. I don't like being on display. So walking around with a bald head or a scarf, that's not my comfort zone. But it's also not fun knowing I could be wearing a wig forever, and that's not totally myself either. I’m living in a weird in-between. Neither way for me is me. And that sucks. Knowing that that might be where I live forever is in the like weird middle. I will never feel comfortable walking around with my head out. Even if I'm 80 years old, that will never be. And as cool as wigs can be, you still know that it's not yours. Like my nieces pull my hair, and I'm like, "Oh, I probably should react," but you don't feel anything. It's weird to not feel a sensation. So that's weird. So realizing that it's a thing is still hard. It's just a weird feeling. At least with asthma, I know what triggers it. And I can fix it so quickly. If I start wheezing, I take an inhaler and I’m fine in 15 minutes tops. But if I keep going and I get a spot, it takes months for that spot to fill in. And you don't know why it happened. You don't know when it's going to happen. You don't know where it's going to happen. That's what's annoying. As much as you can embrace it, it's still never a comfortable feeling. Maybe I'll get there someday, but I just don't feel like that's me. That's just not who I see myself being is the person that, fully embracing, wears a scarf all the time. I just don't see myself fully embracing that, and being comfortable with it.

Bella mentally works through her options, recognizing that where she is now is a liminal space in which none of her options really “feel like me.” Bella recently tried out the option of wearing a scarf on vacation.

> I went on vacation to Hawaii. I wore a scarf out to the beach because wigs are hot. It's hard to put them in a ponytail, and then you have to re-do them. So I finally was like, I'm going to do it. I'm going to go on this vacation and no one knows me. It's going to be hot, and this is just easier. And I walked around like that and it was fine. But walking around like

> that every day, people look at you are not thinking like, "Oh I wonder what that is?" They're thinking cancer. They're thinking I'm recovering because I don't look sick. I feel like you just get a lot more people staring, and maybe that's just me feeling like they're staring. I feel like even if I did this for 15 years, I would think people are starting to stare.

Bella talked more about the meaning of people thinking she has cancer.

> My sister has cancer right now. I don't want people thinking I'm sick. It just sucks. Especially when you try so hard to look not sick. When I take off all my makeup and I don't have any hair on, I don't look great because I don't have the eyelashes. I have some eyebrows, but I don't have full eyebrows. So you do look sick. You don't want people to feel that way and feel sympathetic for you, because I don't need the sympathy. I don't want it from a stranger. If my friend wants to feel bad that she's talking about her hair and she just got it colored, if you want to feel sympathy for the fact that I can't color mine, that's fine. But having somebody when I'm walking down the street look at me like, "Oh, she's so young." My sister is young and that’s what they are all doing to her. And she doesn't want it either, and she's actually sick. And I don't need it. I don't like to feel vulnerable. When you're sick, typically you're vulnerable. I don't feel like that.

Bella carefully distinguishes between appropriate and inappropriate sympathy for her condition. Inappropriate sympathy is unwanted because it suggests greater weakness.

Bella explained that experiencing her sister losing her hair through chemotherapy, while difficult, has been validating for the difficulties she has had with AA.

> This has been a new way that I've been thinking about stuff, because she's dealing with the same looking good issues. It's been hard to watch her because I don't want her to feel the way that I feel. But she's married with kids, and her husband's great, but she just feels ugly and gross. And I get it. But it's hard watching somebody else. When it's yourself you're like, I can deal with it, this is my thing. I've had a harder time watching her with it, and she's had a harder time talking to me about it. We talk about it easily, but then she's like, "Is this uncomfortable for you?" And I'm like, "No, it's nice because we've never been able to relate on this level." And she's like, "Well, I just don't want to make you uncomfortable." And I'm like, "Why would it be uncomfortable?" She's like, "Well, mine's temporary." And I was like, "Well, dad says mine's temporary too! So I could have a full head of hair!" But it's been nice to kind of commiserate together and laugh about it together, because there are funny things. I went

> with her to shave her head, and I think it was harder on me than it was on her because I know how I felt. Having to get used to it’s hard on everybody. You don't want to see your best friend or your sibling going through a hard time, and going through something you've experienced. I already know how hard that is. It's been almost therapeutic to watch her go through it in a weird way. Because her hair is kind of starting to grow back, and I'm so excited for her because it's such a cool feeling. To see it happen and be able to talk about the sensation of it growing back, and the things you feel when you're losing it. She's like, "I stopped wearing makeup." I was like, "Okay." And she's like, "Well my eye lashes and my eye brows are coming out now.” I was like, "Okay." She's like, "I'm trying not to touch them. I want to keep as many eye lashes as possible." And I'm like, "Yeah, I get it. I have none." So it's been interesting kind of talking about it with her too because she's never been one who cares about her appearance as much as me, especially the older she's gotten. She's always been a minimalist, she doesn't wear a lot of makeup or do a whole lot. So to watch her care, I'm like, then it's not as big of a deal that I care. Someone who already doesn't wear a ton of makeup and could care less if she had long or short eye lashes, even she cares that she is losing this. Then I don't feel like such a outlier feeling like this is a big deal, because it's a big deal to you. Not that I didn't think she’d care, but she doesn't pay attention to that kind of stuff as much as I do.

As Bella sees her sister, who she views is relatively unconcerned with appearance, lose her hair, brows, and lashes, she gains a sense that her AA is as impactful as she felt it to be. It is validating to see others recognize the magnitude of the experience.

When reflecting on how she understands her experience of alopecia areata in her life, Bella explains having AA has taught her lessons about priorities.

> It's made me figure out who I am and what I need, and that people like me without hair. Not everybody sucks like I was conditioned to think when I was little. It's kind of been a process to realize that people are actually nice, and they're not all shady and superficial and judgmental. It's been nice in that way because then I feel like they feel more open to share stuff with me too. So I feel like the friendships that I have are deeper than some other people's friendships. I feel like my friends are legit, really good friends. Not that other people's aren't, but I don't feel like everybody's are as strong as mine are. It's really made me figure out who I want as a friend and who I want to be as a person. I feel like it's made me less judgmental. It's been nice to have my friends feel like they can be more open with me

> because they know my biggest secret or insecurity. I feel like it's made me – it sounds stupid – but a better person. But at the same time, I definitely think it held me back from a lot. Like the relationship things and the things that I feel like I can't do because I won't take my wig off and jump in a pool. So I think it's definitely held me back in aspects, but I think overall it's made me a better person to have a problem and be able to overcome it day-to-day.

Through being vulnerable and disclosing about her AA, Bella gains a gift of deeper friendships. She also finds herself having less judgement for others, making her a "better person."

When thinking about her future, Bella predicts her process of acceptance may need to accelerate.

> I see myself having to face facts. I've thought about it more and more: how long am I going to do what I'm doing? I met somebody at support group who has this hair treatment that, again, you take off every night. But it's suctioned to your head. You can't have any hair. You have to completely shave your head to do this so it sticks. But you can swim in it! And it's real hair and it lasts like 3 to 5 years, whereas the one's I'm wearing now are about 1 to 2 years. It's something I have to face facts, that I can't have any hair if I want to go that way, so I've kind of decided that like 3 to 5 years, and who knows it might be even less if I can come to the realization that I'm okay with that. I kind of want to prove that I can get it back. But I also don't want to keep wasting time. I feel like the older I get I'm not going to have the time to get these weekly appointments for 45 minutes, and do I want to spend that time doing something else? Eventually I'm going to have kids and it's just not going to fit into my schedule anymore.
>
> I think in the future I see myself more embracing this is the reality, that it's not necessarily going to come all back and just kind of start getting rid of it, and kind of freeing myself from what it is right now. Just completely owning the fact that I have no hair, and putting on something else. Because when I have kids I want to go in the pool. And I want to be able to do all that stuff. Right now it's one thing to tell my friend I can't go scuba diving, but it's another thing to tell my kid I can't go in the pool. So it's something I need to conquer and find alternative ways. And whoever I marry is not going to care. My kids aren't going to care. So, I eventually see myself just embracing. If it doesn't grow back and stay, I see myself completely embracing the nothing and just kind of getting something that's

> active, something that can be active, something that can go in a ponytail and I can be that normal person that I've been striving to be without my real hair.

Bella is considering ways to have greater freedom, so she can more fully live her life when she becomes a mom and a wife.

The Typical Day

Summary. For much of Bella's typical day, she is unaware of her AA. She puts the wig on at the end of her morning routine, leaves for work, and does not think about it again until looking forward to the relief of removing the wig at the end of her day. Certain things might bring the AA to her mind: if she is outside and the wind is blowing, or if someone compliments her on her hair. Approximately once every 10-14 days, however, Bella finds it difficult to focus on anything but her AA. She takes extra time fixing her wig in the morning, moving one hair after another, arriving late for work. She refers to the uncomfortable feelings that spur this pattern as her "OCD." She manages to not let the experience repeat itself on two consecutive days, but the next time it occurs she feels almost as if she is outside her body watching herself go through the same cycle again. She feels frustrated that she is aware of the process, but feels helpless to control it on that first day.

Detailed description. A typical day for Bella always involves full makeup and hair to keep the AA hidden.

> Okay, my typical day. I get up in the morning. The one nice thing about alopecia is I don't have to shower every day because I'm not smelly. I'm not sweating up a storm or anything weird. Now I throw on a wig so it always looks good, for the most part. So on a typical day, let's say I don't shower. It saves me time in the morning, which is kind of nice. I do currently have half a head of hair so when I do shower I do have to pull

> out the blow dryer which takes about 2 seconds to dry the rest of it. Once I get through that morning stuff, I put on makeup. I have to fill in my eyebrows. I don't ever go out typically without any eyeliner on since I don't have eyelashes, so people always wonder why I'm always wearing makeup. That's kind of my excuse, because one thing I have experienced is when I do tell friends, and they're like, "Oh, my gosh, I just never noticed you don't have any eyelashes." I'm always wearing dark eye makeup so I think it kind of hides that. It's nice to know people don't notice, because I used to wear fake eyelashes. They were a lot of work. And I have contacts, so I'm constantly touching my eyes so dealing with glue and having them fall off, I was more paranoid with them on than without them on. So, I finally gave up on that and just always wear some sort of makeup to hide that. You'll never see me without makeup, which is annoying. It's always full on eye makeup. And then kind of filling in the eyebrows, putting the hair on last, because that's always the worst thing. You're hot. And it's easy to do at the end, it's nice to not have to worry about it while you're getting ready. Then kind of throw that on. Fix it up a little bit, if need be.

She describes the routine as relatively devoid of emotional content: it just happens. Bella clarifies that is not always the case, however.

> I think about AA is if it's a day or two before I'm going to wash the wig and it's really dirty. Those are the days I tend to focus on it a little bit more in the morning, and I'm trying to make it look quote-unquote normal for what I think it should look like or feel like. I do think about it a little more on those days where I'm like, "I just need to get through today, and then I'm washing it and then I'll feel better about it." So I think about it more on those days, too. So towards the end of that 10 to 14 day period, if it's getting kind of heavy, if it's not looking as fresh, I start to wonder if people are noticing and thinking about it as much as I am. Most of the time when those little frustrations and those little moments come up, I don't let it affect the next day. I kind of remember the day before and I'm like, I can't do that again. I can't be 20 minutes late to work, and I can't be prolonging my day just for this. Because it affects my whole day, I'm constantly going to the bathroom and checking it. And I know it looks fine because I spent an extra 20 minutes on it.

She explains more about the process on those more difficult days.

> We talked about me being very OCD with my real hair and just covering things up and making sure everything is hidden. I can tell when I'm anxious now because I get very particular about my wig. Which is really

> funny because it always looks the same, it always looks fine. But, when I'm having kind of an anxious week or an anxious month I tend to focus on even the wig hair. I’m just extremely uncomfortable. It's one of those things that has just been drilled into me. It feels frustrating because I know I'm doing it too. I want it to look as natural as possible in the front so I think that's my new source of OCD is making sure every hair is in the right place to make sure it still looks normal and natural. Not being able to overcome that is what's just so frustrating. I can't stop playing with it and I can't stop moving a few strands here and there. It ends up always making it worse, and then I have to start over again. So it's a vicious cycle. It's absolutely like that's the number one thing is it's frustrating. It's like you watch somebody else do things and you're like, "Oh, my gosh, stop doing that!" So I always have like an out-of-body experience every time that anxiety or OCD or whatever you want to call it kicks in. Because I know it immediately when it's happening. And it's usually when I'm stressed and it's usually when I'm really masking other things that are going on. Typically that won't happen 2 days in a row – I won't let it happen 2 days in a row. Kind of the next day I throw it on, and I hardly will look at it. I just put it on and not focus too much on anything. It feels better. But it's a weird cycle because it happens again.

Some days the AA is prevalent on her mind.

Bella explained that the AA does not often come into her mind on non-anxious days, with a few exceptions.

> I don't necessarily think about alopecia every day, but there are days. Outside elements – I’m a huge hater of wind because my hair doesn't naturally flow like other people's. It doesn't look the same, I think it looks fake. So that's probably the only other time during the day that I think about it is when I'm with coworkers, and we're outside and the wind is blowing and I'm like, "Oh my gosh! Like what does my hair look like right now?" So that's kind of the only other time I think about it. It's just like hyperawareness. It’s more of that anxious feeling. I'm like, "Oh, my gosh, like, are you looking at me?" Like, we're having a conversation, are you looking? What's happening right now? It doesn't look right. So it's more of that. I can't think of a better word than just anxious. And it's like a judgment, are you looking at me and really listening to our conversation or are you looking at me and being judgmental and trying to figure out what's going on?

Another exception is when the conversation at work turns to hair, either hers or someone else’s. She provides a few examples.

> Yeah, I guess other times it kind of comes up in my mind is when other people are talking about changing their hair or doing something different, or when people ask me, "Why don't you do anything different?" I do kind of stick to the same hairstyle, which is always kind of a bummer because everybody wants to at least do something different every once in a while. That's the only other time feelings about it come up. And that's kind of, the feeling of that is more of just kind of a bummer. It's kind of like a longing for wanting to do that. But, I can't participate in the conversation so I kind of withdraw and kind of try to get out of those conversations as much as possible. I tend to kind of remove myself from the situation, not even saying anything. If we're at work is typically when these conversations happen. I just go back to the work I'm doing and pretend like I've got too much to do to have a conversation about this. Other tendencies, if I'm stuck participating it ends up either being, most of the time I either make a joke or I make up some sort of lie to have a reason behind it. Like I said, I've gotten really good at lying and making up excuses for why I don't do certain things.
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> One of my best friends now, when she didn't know about it she was like, "Oh, you just never wear your hair in a ponytail." I told her I thought she might have known something was up because she kind of called me out. We were out for dinner with a bunch of work people and she was like, "You never wear your hair in a ponytail, I've never seen you." She's like, "Just pull it back, I want to just see what you look like." I was absolutely put on the spot. I hate attention on me in general, let alone attention on me having to do with my hair makes it 10 times worse. I kind of gently pulled it back to make it look as natural as possible, but also kind of acting like it was no big deal. But inside I was absolutely dying and so uncomfortable, and just ready to get the hell out of there.
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> Even when it's positive attention, when people are like, "Your hair always looks so good! I don't know how your hair always looks so great!" I always get uncomfortable. I just don't handle anything well having to do with the spotlight being on my hair. I think my heart races every time. But I also think I get a little tense. And I'm quick to change the subject. If somebody compliments my hair, I'm like, "Oh thanks." Then I move on quite quickly. I just don't want to dwell on it. I just don't want to sit there and make it seem awkward, like I'm hiding something either. I feel like I'm quick to jump to something else. A lot of the times it happened, it doesn't happen a lot anymore, but it used to happen a lot when I'd be with a friend. Often if I'm with that person they know about it so they'll jump in and say something and make it a little less awkward.

Bella manages the discomfort in these situations by trying to casually duck out or play along.

Bella explains the end of her day can also bring AA to mind, in a rather neutral way.

> So no on a typical day I don't think about it until it's the end of the day and I don't have any plans, and I'm like, "Oh, my gosh! I can go home and take my hair off." Because immediately when I get home it comes off right away, if I'm not going anywhere it comes off immediately. And if I go to my parent's house it comes off immediately. So anywhere I'm going where I'm comfortable it comes off, so I always look forward to that at the end of the day. So that's the only other time I kind of think about where it's like, oh, my gosh I get to go home and take it off. It's always a great feeling because you can itch it. Because it doesn't itch well on top, and that's where I'm the most itchy. So it's like, I get home and I immediately scratch my entire scalp off because it feels so good. Otherwise maybe I try to go sneak off to the bathroom to get a good itch in when I need to.

Bella stated when she does not go home or somewhere comfortable, "Then I wear it all night." She explained on a typical day where she does not go home, her AA does "not really" come into her mind.

> Not really. Most of the time it feels normal, unless it's one of those anxious days where I almost wish I didn't have plans just so I could go home and just get rid of it. But, for the most part, most days I'm completely fine with it.

Again, Bella's typical days continue to be relatively free from thought or concern about her AA, with the exception of the more "anxious days."

Bella explained that another situation in which she might think about her AA is when she suspects she may have lost more.

> Things that used to signify that I was getting a spot don't necessarily mean that anymore; if it's itchy or if it's kind of tender. If things are itchy in places where I've had hair for a long time, I'm like, "Okay, wait a minute.

> What's happening?" Or I start thinking I'm seeing spots or regress. I try not to analyze my head too much until I go and see my hair specialist because I don't want to stress myself out over nothing. I've learned to do that. That's something I've been able to kind of take a step back from. Unless it's an obvious change. But sitting there and staring in the mirror, I don't do that with my head because you can go cross-eyed. I would almost need to mark my head every day with a Sharpie to keep track of it. That's why I kind of just stopped looking. I focus on my wig, that doesn't change every day. At least that's something that I know is consistent. I'm just being kind of a nutcase about it.

Bella has found a way to mentally put potential changes in her AA out of her mind, making this now an infrequent occurrence.

References

Wertz, F. J. (2011). A phenomenological psychological approach to trauma and resilience (pp. 124-164). In F. J. Wertz, K. Charmaz, L. M. McMullen, R. Josselson, R. Anderson, & E. McSpadden (Eds.), *Five ways of doing qualitative analysis: Phenomenological psychology, grounded theory, discourse analysis, narrative research, and intuitive inquiry.* New York: The Guilford Press.

Van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing.* Walnut Creek, CA: Left Coast Press, Inc.