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The Bald Truth:
Determining the need for a Canadian Alopecia Association

By

Bonnie Lipton
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Abstract

The main objective of this research was to determine if Canadians with alopecia areata and their families perceive there is a need for the creation of an organization providing support and services to them in Canada. Previous research has documented the psychological devastation resulting from hair loss in children and adults of both sexes. Alopecia areata is present in approximately 1-2% of the Canadian population (Canadian Dermatology Association, 2002) yet this disorder remains relatively unknown and misunderstood by the medical community and the general population. Services for Canadians with alopecia areata are limited to interactions with family physicians, dermatologists and international resources. Collectivity is integral to the empowerment process (Saleeby, 2002). The value systems, principles, and practices of feminist organizing and the self-help movement are presented as viable models for organizing a Canadian community of individuals with alopecia areata.

An exploratory research project was designed to assess the needs of Canadians coping either directly or indirectly with alopecia areata. A total of 134 Canadians completed a self-administered web-based questionnaire which yielded both quantitative and qualitative data. The results indicated that 93.8% of respondents feel there is a strong need for the creation of a Canadian alopecia areata association. The concepts of isolation, being bald and "invisible," and breaking the silence emerged from the qualitative analysis. It was clear that Canadians with alopecia areata experience both emotional and physical isolation as they struggle to find the most basic of services. Respondents exercised their voice and broke the silence by sharing their experiences, thoughts, ideas, and hopes for alopecia areata in Canada. It is apparent that the needs of this sample of Canadians coping with alopecia areata are not being met.

Acknowledgements

To my participants, thank-you for sharing your experiences, opinions, ideas, and stories. I am touched by your courage and inspired by your vision for service to Canadians with alopecia areata. It is my greatest hope that this dream may one day become a reality.

My sincere gratitude to the National Alopecia Areata Foundation for helping me reach Canadians with alopecia areata. Attending your conference motivated and empowered me to do this research. Thank-you for your phenomenal dedication to individuals with alopecia areata.

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Finally, I would like to dedicate my thesis to my parents, Marilyn and Keith. You made so many sacrifices for my happiness and well-being as a child and you always made me feel beautiful, special, and "normal". Through the years, you have helped me conceptualize alopecia areata as a gift rather than a loss. Thank-you for the hours of phone support, for helping me see my strengths, and for always believing in me and my work. You are my mentors and I share this accomplishment with you.

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Chapter 1 - Introduction

Alopecia Areata is an autoimmune disorder present in approximately 1% of the Canadian population (Canadian Dermatology Association, 2002) with 60% of reported cases developing in individuals under the age of 20 years (Liakopoulou et al., 1997; Thompson & Shapiro, 1996). This disorder causes unpredictable hair loss in men, women, and children of all ages and in cultures across the world. "The earlier the onset, the poorer the prognosis. Relapses occur in 40% to 50% of all cases, and the condition may be permanent in 25% of them" (Liakopoulou et al., 1997). Alopecia Areata is characterized by the sudden appearance of circular bald patches and may progress to the loss of all scalp hair called alopecia totalis or the complete loss of body hair known as alopecia universalis (Thompson & Shapiro, 1996). There is currently no cure for this condition and existing treatments are unreliable. While alopecia areata is generally considered to be medically benign, it has been shown to have a devastating impact on the psychological health of patients (NAAF, 2004; Thompson & Shapiro, 1996).

Alopecia areata is considered to be a harmless physical condition, however it is important to recognize that the "coping mechanisms for surviving hair loss are as critical as those for surviving any serious disease" (Thompson & Shapiro, 1996, p. 9). Doctors, nurses and patients alike identify hair loss as one of the most devastating side-effects of chemotherapy treatment (McGarvey, Baum, Pinkerton & Rogers, 2001; Hughes, 1987; Munstedt, Manthey, Sachsse & Vahrson, 1997; Thompson & Shapiro, 1996). The reality remains that hair has great value in society as a symbol of beauty, style, health, and vitality. Hair occupies an integral position in the composition of our self-image and identity. "The appearance of our hair transmits many complex and intertwined messages about ourselves to the world. In turn, these messages rebound upon ourselves, facilitating definition of self in relation to society" (Levine, 1995, p. 80). We take comfort in the stability of our self-concept and this constancy is fundamental to our mental health. The loss of our hair to alopecia areata robs of us this certainty, choice, and sense of personal control. "When control is lost, so is our confidence and self-esteem" (Thompson & Shapiro, 1996, p.8).

The body of this thesis is organized into six chapters. Following this introductory chapter, a conceptual framework presents concepts such as vulnerability in research; working from a feminist perspective; beauty and femininity; the social, cultural, and religious meanings of hair; and the current state of service to Canadians with alopecia areata. Next, literature on feminist organizing and the self-help movement are reviewed. Chapter four presents the research objectives and methodology. Following the method, the quantitative and qualitative results are outlined. A discussion of the findings, implications for research and practice, and a conclusion close this thesis.

Chapter 2 – Conceptual Framework

Vulnerability in research: an exercise in reflexive ethnography

I identify as a white, middle-class, young, heterosexual, feminist, Atlantic Canadian woman with alopecia areata. My experience as a Canadian woman with alopecia areata has both inspired and informed this research. One of my goals for this thesis was to form a connection with the reader and bring the reader into "my world" in order to establish an understanding of the origin and need for this research. In this effort, I felt it to be necessary to share parts of myself and my experience as a Canadian woman with alopecia areata. This project required a great deal of introspection and personal vulnerability; a task which has challenged me throughout this entire thesis process. I learned to let go of the idea of myself as an objective observer and write from a first-person voice. This writing style defied all the traditional social science research principles entrenched during my undergraduate education.

Literature on reflexive ethnography validated my choice to step outside the traditional parameters of research and locate myself and my experience in the research. According to Ellis & Bochner (2000), reflexive ethnography involves the use of the author/researcher's own personal experience to explore and/or illuminate that of the participants/group/ culture under study. Reflexive ethnography exists on a continuum and my research falls at one end of the range as I started and introduced my research from my own experience versus focusing my investigation on my personal experience (Ellis & Bochner, 2000). Behar (1996) cautions "Vulnerability doesn't mean anything personal goes. The exposure of self who is also the spectator has to take us somewhere we couldn't otherwise get to" (p.14). I felt that the inclusion of my personal connection to this research would facilitate an intimate view of the reality of alopecia areata and legitimate how and why I initiated and conceptualized this research.

The autobiographical voice associated with reflexive ethnography exposes the reader to the emotion of experience and promotes learning, understanding, tolerance, and humility in both the author and reader (Ellis & Bochner, 2000). Unlike detached writing, vulnerable writing evokes a vulnerable response (Behar, 1996). Reflexive ethnography promotes learning as we get "exposed to local stories that bring us into the worlds of experience that are unknown to us, show us the concrete daily details of people whose lives have been underrepresented or not represented at all, help us reduce their marginalization, show us how partial and situated our understanding of the world is" (Ellis & Bochner, 2000, p. 748).

Focus of feminism

Historically, the majority of research, medical and otherwise, has been devoted to male issues. This trend exists even today. While prevalence rates of alopecia areata are approximately equal between both sexes, I believe that women and men experience hair loss in different ways and degrees. I do not wish to minimize the experience of men with alopecia areata, but my personal experience as a woman with alopecia aratea, coupled with my feminist ideology has informed my decision to focus on the unique experiences of women losing their hair in a society obsessed with female "beauty."

As a woman (and more specifically a bald woman), I feel bombarded by media, cultural, and social objectification of the female physique. I have adopted feminist values to combat a patriarchal belief system which reduces women to their body. Yoder (2000) states "feminism means valuing women and their experiences, a concern for equality of power, the need for change and activism, and the belief that gender is created and defined by our culture" (p. 5). This definition resonates with my values and practices as a feminist. My mother embodied what I would describe as "action-oriented feminism" where she challenged traditional stereotypes of women, modeled strength of body and mind, crossed gender roles, valued domesticity as self-employment, and empowered me to find my voice and use it. I am hesitant to categorize my feminist beliefs as I believe there is no "right way" to be a practicing feminist. My mother did not use the word feminism with me as a child - she lived it in her daily life. To me, feminism is more than a word, more than a theory, and much more than a stereotype. My feminist values and practices are difficult to neatly categorize or label. I conceptualize feminism as a daily struggle to resist and challenge an overwhelming flood of images and messages that disempower women and all people of lower societal status.

As a feminist, my research was informed directly by feminist literature on hair, beauty, body image, and organizing. I believe it is necessary to educate the reader about alopecia areata as a disorder and the possible implications of being bald in a society that values hair. It is my goal in this introduction to orient the reader to my story and my critical reasoning for this research. In this effort, I made the decision to present literature on hair, beauty, body image, and alopecia areata in this chapter. In chapter two, I focus on the structural components of organizing in a review of the literature on community, feminist organizing, and the self-help movement.

The quest for beauty in North American society

The value of female "beauty" in our culture cannot be denied. Fashion magazines, television, movies, music, and advertising communicate very powerful messages about female physical appearance and status (Chapkis, 1986; Maine, 2000; Wolf, 1991). Mcdowell (2000) states,

> Looks, girls learn early, collapse into a metaphor for everything else. They quickly become the defining criteria for our status and our worth. And somewhere along the line, we stop believing in our own beauty and its dominion. Subsequently, we stop believing in the power of our minds and our bodies (p. 16).

I once came across a quote in a women's magazine that stated "Beauty is easy when you stop trying so hard." At first, I interpreted this message as empowering; we do not have to strive to obtain some culturally prescribed notion of beauty. True beauty cannot be created outside of ourselves. It must first be nurtured within. I keep this quote visible in my home, but I have come to the realization that these words do not mean anything to me as I put on my makeup, fix my wig, choose my clothes, and scrutinize my body each day. I still *try*. The question is: why do I try so hard and for whom?

American consumers spend over 20 billion dollars on beauty products each year. Contemporary advertising preys upon the insecurities of women and has been named "the worst offender to women's well being" in a United Nations report on the status of women (Maine, 2000, p. 78). "Beauty" is a quality that is neither timeless nor universal; it is for sale. The beauty industry is pervasive and powerful with the diet, cosmetics, and cosmetic surgery industries generating profits exceeding 53 billions dollars per year (Wolf, 1991, p.17). Western culture and media impose a narrow definition of female beauty that reinforces judgment of women based more on their image than by their accomplishments (Maine, 2000). Naomi Wolf (1991) says,

> We are in the midst of a violent backlash against feminism that uses images of female beauty as a political weapon against women's advancement: the beauty myth. ...[T]he ideology of beauty is the one last remaining of the old feminine ideologies that still has the power to control those women whom second wave feminism would have otherwise made relatively uncontrollable: It has grown stronger to take over the work of social coercion that myths about motherhood, domesticity, chastity, and passivity, no longer can manage. It is seeking right now to undo psychologically and covertly all the good things that feminism did for women materially and overtly (pp.10-11).

Hair

While beauty is culturally defined and subject to the changing desires of each generation, head hair has been an enduring symbol of femininity in world myth, folklore, legend, religion, literature, and poetry (Cooper, 1971; Levine, 1995; Firth, 1973). Copper (1971) notes "... hair is second only to eyes as the physical attribute most celebrated and praised by lovers and writers" (p. 222). A commanding nonverbal tool, hair can communicate class, identity, politics, mood, health, status, age, custom, fashion, social statements, and social control (Cooper, 1971; Levine, 1995; Firth, 1973). Cooper (1971) asserts "it is not surprising that in a largely male-dominated world, in which far stricter standards of sexual behaviour have been imposed on women, the clear badge of sexual status has been most rigidly applied to the female sex" (p. 144). The color, texture, softness, and scent of head hair are intimately linked with female sex appeal and have been used to declare sexual status throughout history. Hair has long been romanticized in our culture. It has been the chief love token of all ages; it is magical and a keepsake" (Copper, 1991).

The power of hair: personal reflections

As a child, I read fairy-tales filled with beautiful women, their hair black as ebony, magnificent and long, or fine as spun gold. The sentiment and attraction of female hair is heightened by folklore and literature. A heroine's hair is described as soft and smooth, like silk or satin, and it is characteristically tumbling, flowing, floating, rippling, gleaming, tousled, or caressed. Hair has been an imagined feeling my entire life; such experiences of hair exist only in adjectives and verbs. I do not remember having a full head of hair; I do not know what it feels like to run my fingers through my hair, feel it blowing in the wind, or have it stroked by a loved one. I want to know and I always have.

My parents noticed a bald spot the size of a dime when I was only 18 months old. This spot grew in but was soon replaced with many more and by the age of four, I had lost all of my head hair. As a young girl, I assumed I was "normal". My parents always reinforced my many blessings. I was lucky because there were children who could not see or hear, or were missing an arm or leg. I distinctly recall the first time I realized that I was "different" at the age of four years. My baby brother and I had our portrait taken and I had worn a summer dress with a matching hat to the studio. Naturally, I removed my hat for the photo. The male photographer was shocked and immediately asked me to put my hat back on for the pictures. His fearful reaction to the sight of my bald head made me feel like there was something wrong with me. I chose to wear a wig when I started kindergarten soon after. My varying degrees of hair loss have been concealed under a hair piece for almost 20 years.

My wig has become an extension of myself: it is a comfort, a protector, a friend. I recently purchased my first quality human hair wig. This occasion caused me to vomit two hours prior to the final sale, cry during the hair cut, praise the owner of the salon (whom I had just paid $2200) as though he was my savior, sob in my bedroom, and stare at myself in mirrors for weeks after. This was an emotionally exhausting and financially devastating event, but for the first time in my life I felt pretty, and more importantly, feminine. I liked how I looked and this feeling allowed me a new sense of self-confidence and, yes, power. I was both shocked and ashamed of my reaction to this new wig. As a young girl and a grown woman, I valued education as the key to power and the door to change. The embarrassing truth is that my new hair made me feel more powerful in a single moment than any other experience in my life. And so I have a confession, I am an educated feminist under the influence of the cultural expectations of women. I want to be beautiful, I want to be feminine and I am willing to pay a price to achieve it. I know that I am not alone.

The historical and cultural meanings of hair

"Hair is the object of intense elaboration and preoccupation in many societies; seemingly the most superficial part of the human body, its meanings are nevertheless deeply rooted in culture" (Delaney, 1995, p. 53). Religious and cultural symbolism of hair has a global presence. In many religions, the act of shaving head hair marks a transition from one social state to another and often symbolizes celibacy or chastity. Christian monks, Hindu priests and Hindu widows have shaven heads. Buddhist monks have hairless heads and bodies. In contrast, hairiness in a man has served as a sign of his virility, strength, and power (Cooper, 1971; Firth, 1973). For example, the strength of the Biblical figure, Sampson, was completely dependent upon his long head of hair.

Eilberg-Schwartz (1995) states, "The female head is a particularly rich and important site in the symbolization of gender and in the linking of gender to the transcendent values of specific cultural or religious systems" (p. 1). Among many cultures and religions, female head hair is a source of erotic symbolism. Hair practices of covering and concealment symbolize sexual control (or male "ownership" of intimate partners) and communicate female social status (Levine, 1995). For instance, the hair of Orthodox Jewish females is shorn and bewigged immediately prior to and throughout marriage (Eilberg-Schwartz, 1995). The head and hair of Muslim women is veiled with the arrival of puberty. Female head hair is a universal object of sexual attraction and, a symbol of the strength of a woman's femininity and its power to "move male desire and love" (Firth, 1973, p. 268). According to St. Paul, "a woman's long hair is a glory unto her" (Cooper, 1971, p. 65).

What is it about hair? Hair has qualities which recommend it as an instrument for social action. In contrast to other body parts, hair is unique as it is multiple, detachable, renewable, and pliable (Cooper, 1971; Firth, 1973). Its texture, color, and distribution varies across the human race. Hair is "second only to skin color as a physical sign of racial difference" (Cooper, 1971, p. 20). Hair, simply by its natural characteristics, implies social differentiation and can communicate age, health, or illness.

The head is a display point. Hairstyling, like cosmetics, invites the gaze of others and draws attention to the head. By highlighting our features we play on, and provoke, desire. We are aware of the viewer. The style of hair can indicate social, economic, intellectual, or sexual status (Cooper, 1971). We make assumptions and judgments about an individual's sexual orientation, generation, class, morality, political and religious values, and mood when we see specific hairstyles or practices related to hair care (Eilberg-Schwartz, 1995; Firth, 1973; Edut, 2000). The mere mention of words such as: afro, mullet, perm, mohawk, dreads, hippie, shag, bob, pixie, bouffant, rattail, and beehive invoke certain images of and ideas about an individual or group.

> In wearing of the hair one may recognize custom, or standard modes of behaviour, and fashion, or an oscillation of focus on particular styles. But in addition to these norms, the manner of wearing the hair has sometimes been used to make a more personal statement" (Firth, 1973, p. 272).

We are a society obsessed with hair. The significance of hair is reinforced every day in Western culture. Hair occupies an integral position in both fashion and image. Fashion, says Delaney (1995) is "itself a kind of secular religion of innovation" (p. 81). I cannot turn the television on without seeing multiple commercials for hair products. A hair style can define a generation. Celebrities such as Farrah Fawcett (*Charlie's Angels*) and Jennifer Aniston (*Friends*) have become "hair trendsetters." Women across North America have copied the hairstyles of both actresses. *Felicity*, a critically acclaimed television show on The Warner Brothers network, experienced a 30% drop in ratings during its second season. Industry experts, WB network staff, and media believed this drastic plunge was initiated when the actress, Keri Russell, who played the title character, cut her long, curly hair short (Kaplan, 2000). A single haircut was blamed for the threat of the show's cancellation. An unsatisfactory haircut can bring a woman to tears while a good one can be a source of strength and confidence. Our hair has a great deal of personal and public meaning.

Being bald in a world obsessed with hair

Given the value of hair in our society, it may be difficult to conceptualize bald as beautiful. In my opinion, however, beauty is not dependent solely upon hair. Some of the most beautiful women I have ever met were bald. Hair shields the rest of our facial features: eyes, lips, nose, and cheekbones. The absence of hair allows the dynamic beauty of each of these features to shine through with radiance. The problem, however, remains that beauty is defined *for* women, not *by* women. According to Western culture, a bald woman is either sick with terminal illness, a lesbian, a radical feminist, or a rebel; while, a bald man can be sexy, distinguished, and powerful. For example, Greer (1999) states: "What is pathological behaviour in a man is required of a woman. A bald man who wears a wig is a ridiculous figure; a bald woman who refuses to wear a wig is being stroppy and confrontational" (p. 24). I recently found a Canadian-made greeting card at a local gift store with the following statement: "Women will never be equal to men until they can walk down the street with a bald head and a beer belly and still think they are beautiful."- I wanted to buy every copy in the store.

Given the positive values attached to hair and its intimate association with femininity and beauty, it is not surprising that the loss of head hair can be personally and socially devastating (Firth, 1973; Thompson & Shapiro, 1996). Literature exists on the negative impact of alopecia areata on the psychological functioning of individuals with this disorder and specifically, on girls and women. A study of 31 adults with alopecia areata revealed a high rate of major depression and generalized anxiety disorder (Colon et al., 1991). Research on the psychological functioning of children with alopecia areata has discovered a high incidence of psychopathology (Colon et al., 1991; Liakopoulou et al., 1997, Reeve, Savage, & Bernstein, 1996).

Anxiety, depression, problems with socialization and the regulation of aggression were evident in a study of 33 school age children with alopecia areata. Observation of these children highlighted the apparent presence of sadness and shame among this sample of children with alopecia areata (Liakopoulou et al., 1997). The findings of this study by Liakopoulou et al. (1997) suggested that both children with alopecia areata and their families require psychiatric assessment and, in many cases, treatment. Reeve, Savage & Bernstein (1996, p. 1521) suggest that "mental health treatment may most appropriately be directed toward helping the patient cope with the disorder through support and counseling."

Girls with alopecia areata, in particular, were found to have more significant internalizing and externalizing syndromes than boys with alopecia areata and control groups of both sexes (Liakopoulou et al., 1997). They seem to suffer more anxiety and depression than their male counterparts. Hair is equated with femininity, attractiveness and sexuality in women; therefore, it is likely that girls and women alike would experience more depressive reactions to alopecia areata. Studies of women with androgenetic alopecia, "a hereditary hair-loss pattern of diffuse central thinning" (Cash, Price & Savin, 1993, p. 568) reveal that hair loss causes women to have more social anxiety, lower self-esteem, less sense of control over their lives, negative body-image feelings, and experience severe maladjustment to their hair loss (Cash, 1999; Cash, Price & Savin, 1993; Girman et al., 1999; van Der Donk et al., 1994).

Male-pattern baldness is generally an unwanted experience for most men and is associated with lower body-image satisfaction however, "balding men actively cope with their distress, and most seem to retain the integrity of their personality functioning" (Cash, Price & Savin, 1993, p.568). Wells, Willmoth & Russell (1995) investigated the correlation between male hair loss and psychological distress in 182 men with varying degrees of hair loss. Results concluded that increasing hair loss caused a loss of self-esteem, depressive tendencies, greater introversion, and feelings of unattractiveness at all ages with symptoms being particularly significant in younger men. "Far from a laughing matter, male hair loss is clearly associated with a marked decrease in psychological well-being" (Wells, Willmoth & Russell, 1995, p. 342).

It seems too simplistic to place a label on adults and children with alopecia areata and reduce their problems to psychopathology. Critical analysis of the above studies left me questioning their credibility. They did not appear to have reliable and valid research methods. I was unable to find any literature on the possible environmental factors which may cause or contribute to a decline in the quality of life of individuals with alopecia areata. There was no mention of access to support services or lack, there of community organization, the impact of the social construction of hair and beauty, or the possible isolation effects of coping with an uncommon disorder. It is my opinion that further research with more rigorous methodology is required before assumptions and/or correlations are formed between alopecia areata and psychopathology.

It is an undeniable fact that life is altered by hair loss. Services for Canadians with alopecia areata are limited to interactions with family physicians, dermatologists, support affiliates with the National Alopecia Areata Foundation in the United States, and international internet resources. Individuals and families coping with alopecia areata in Canada lack a national body of support and representation. Given the vast geography of Canada, boundaries are present in the development of a collective identity, network of support, and resources for individuals with alopecia areata.

As a woman living with this disorder for 22 of my 24 years, my spirit has been challenged and my heart broken by the isolation I experienced as an Atlantic Canadian coping with this condition. My identity development, self-confidence and sense of self-worth have been challenged by my struggle to “fit in” with the dominant society. The fact is I have a significant physical difference from the majority of the population and I have often desired a sense of community with other Canadians with alopecia areata. I believe the absence of a national organization representing and advocating for individuals with alopecia areata in Canada contributes to the silencing of our stories, the devaluing of our experiences with this condition, and the societal misperception and misunderstanding of our baldness. “People feel vulnerable when they think they are alone in facing a problem” and this contributes to the experience of helplessness among individuals (Rubin & Rubin, 2001, p.5).

Resource Inventory

I conducted an informal resource inventory of services available to Canadians with alopecia areata through use of the internet, support group leaders in Canada, and the National Alopecia Areata Foundation in the United States. Currently, services available to Canadians with alopecia areata include the following. The Canadian Dermatology Association, The Canadian Hair Research Foundation, and The University of British Columbia Hair Research and Treatment Centre. These organizations provide medical and research information on alopecia areata. The Canadian Hair Research Foundation (www.hairinfo.org) is the most specialized organization in Canada addressing education and medical research of hair conditions such as alopecia areata. This organization was established in 1999 by accredited and reputable Canadian dermatologists as a research-focused organization. The mission of the Canadian Hair Research Foundation includes "sustaining continuous education and medical research into hair and hair-related conditions in order to better inform interested individuals and provide improved care for all those with hair disorders" (Canadian Hair Research Foundation, 1999). Organized support contacts/groups are available in Nova Scotia, New Brunswick, PEI, Quebec, Ontario, and British Columbia.

The majority of support and education resources for Canadians with alopecia areata and their family members are coordinated through the National Alopecia Areata Foundation (NAAF) in the United States. Services available to Canadians through this organization include phone support lines, brochures, quarterly newsletters, an educational video for children, an annual conference, and an informative website including monitored message boards for children, adolescents and adults with alopecia areata. Five of the above Canadian support groups are affiliated with the National Alopecia Areata Foundation.

Collectivity is integral to the empowerment process (Saleeby, 2002). The Canadian Hair Research Foundation (2000) cites that one in four Canadians experiencing hair loss have no idea who to turn to for help. It seems imperative to determine if there is a need for the creation of a national organization of representation, support, and advocacy for Canadians with alopecia areata. We are, in essence, a community of interest and identification as a "group of individuals who share a sense of identity and belonging because they have in common some characteristic, interest, or life experience" (Sullivan, Steinhouse & Gelfand, 2000, p.242). Currently, our geographic boundaries as a community are virtually unrecognized as we have become enmeshed with our American counterparts.

The National Alopecia Areata Foundation

As a Canadian with alopecia areata, I tend to identify with the subjective, internal, and personal components of the strong social community which was originally established in the United States and proceeded to cross all borders and reach out to individuals with alopecia areata on a global scale.

> The mission of the National Alopecia Areata Foundation (NAAF) is to support research to find a cure or acceptable treatment for alopecia areata, to support those with the disease, and to educate the public about alopecia areata. The mission is accomplished by: (1) Funding research and research workshops that add to the scientific knowledge about alopecia areata, its causes, and different treatments; (2) Providing local support and education for people with alopecia areata and their families; (3) Informing the public about alopecia areata; (4) Advocating the concerns of people affected alopecia areata; (5) Creating and distributing educational materials to health professionals as well as those affected, so that all may better understand alopecia areata (NAAF, 2004).

This North American community facilitates information, support, and friendship. It has carried Canadians with alopecia areata on its journey to empowerment.

It has been my experience (through direct use of American services and conversations/interactions with many Canadians with alopecia areata), that the Canadian contingent of people with alopecia areata are becoming aware of the objective and political components of community and the need to address our inherent differences from our American neighbors. The reality is that physical access to service, advocacy to government, public education, funding, and research is compromised by the fact that Canada is not America. Geographic boundaries and structural differences do exist between these two neighboring countries. There are clear limits to the extent to which one country can serve another. I am saddened by the current state of support services for Canadians with alopecia areata. Knowledge of the amazing services available to Americans by their National Alopecia Areata Foundation has allowed me to see that we, as Canadians with alopecia areata, do not have the help we need and deserve.

Chapter 3 - Literature Review

"Organizing involves mobilizing others into action in ways that empower both the individuals involved and their broader community" (Rubin & Rubin, 2001, p.119). Community organization is an active process of deliberate change to improve and sustain the quality of life of a community (Berkowitz, 2000). There are many different approaches to organization and social action. The objectives of this study include: the determination of the possible role and objectives of an organization serving Canadians with alopecia areata, type and method of service delivery, and challenges in the process of *organizing*. The value systems, principles, and practices of feminist organizing and the self-help movement are presented as viable models for organizing a Canadian community of individuals with alopecia areata.

What is Community?

Communities perform a variety of functions including the integration of individuals into society and the connection of personal histories, individual loyalties, and private attachments (Howarth, 2001). They "embody cultural practices, shared meanings and common values" (Howarth, 2001, p. 227). As human beings, we feel the need to locate ourselves in the social world. Fulfillment of this need occurs through membership in community. The traditional concept of community is associated with a geographical area such as a neighborhood, town, city, or rural region. This conception of community is what Dalton, Elias, and Walton (2001) would call a *locality* community. A sense of community evolves from attachment to place as interpersonal relations between community members result from proximity. In contrast, a *relational* community is formed through interpersonal relationships that are not limited to location or geography

(Dalton et al., 2001). While the distinction is imperative to this study, it is important to note that these two concepts of community are not mutually exclusive.

Individuals with alopecia areata form a relational community as our interpersonal relationships are based upon shared experience rather than location. According to Dalton et al. (2001) and van Uchelen (2000), the elements of a psychological sense of community include membership, influence, integration and fulfillment of needs, and shared emotional connection. "Shared emotional connection is considered the definitive element for true community" (Dalton et al., 2001, p. 194). It is clear to me that shared emotional connection is indeed what brings individuals with alopecia areata together and sustains the many chat rooms and informal web pages that allow a sense of community to form globally amongst us.

Given the assumption that shared experience and emotional connection are the defining elements of the community of individuals with alopecia areata, it is difficult to establish a clear sense of community related to geography. Dalton et al. (2001) indicate that Western societies have experienced a decline in the sense of community in localities as individuals have become more involved in relational communities. The ever-present threat of dissolution of geographical community is echoed by Howarth (2001) as she states "Urbanization, migration, globalization, new medias and technologies have dissolved the significance of place in the late modern world, and so too threaten the physical geography of community" (p. 225).

Feminist Organizing

The foundation of women-centered organizing was the empowerment of individuals through private-sphere relationships and the development of a network of relationships in a community. In feminist organizing there is an emphasis on community building, collectivism, caring, mutual respect, and self-transformation (Stall & Stoecker, 1998). Feminist organizing values nurturing, consensus decision making, and collaboration (Beck & Eichler, 2000). Central to this model of organization is its holistic approach to working with communities (Bradshaw, Soifer, & Gutierrez, 1994). There is an attempt to remove the dichotomy between the organizer and community or the idea of expert and non-expert (Bradshaw et al., 1994). Organizing occurs in a collective, nonhierarchical, participatory manner (Acker, 1998).

One of the ultimate goals of feminist organizing is empowerment that can be achieved both through process and product (Bradshaw et al., 1994; Stall & Stoecker, 1998). Empowerment is viewed as a process where members lead their own growth process, develop a positive self-concept and self-confidence, assume a more critical worldview, and build individual and collective skills and resources for political and social action (Bradshaw et al., 1994; Stall & Stoecker, 1998). Feminist organizers assume the role of both facilitator/mentor and learner (Bradshaw et al., 1994). Traditional power differentials and/or hierarchical dependency is minimized as the organizer learns from and gives to the community. Leadership is seen as a teaching process where the organizer models "group centered" leadership. This conception of leadership values the participation of all members and believes in the capacity of all to be leaders/organizers (Stall & Stoecker, 1998).

Acker (1995) stressed the importance of distinguishing between "organization" and "organizing." The use of the term organizing recognizes that "agency resides in people, not in abstractions such as an organization" (Acker, 1995, p. 137). Power, therefore, does not reside in the organization or need to be taken from someone else as suggested in the corporate world of competition and exploitation. Stall & Stoecker (1998) present the feminist idea of "co-active power" which is "based on human interdependence and the development of all within the group or the community through collaboration" (p. 741).

"Feminist organizing occurs in opposition to the existing ways of doing things" (Acker, 1995, p. 139). The dominant masculine practice of organization regards community organizing as a method to gain power while the woman-centered model views organizing as process of community building and empowerment (Taylor, 1999). This means, however, that feminist organizing must fight for survival in an organizational world where hierarchy, divisions of labor, timing, and procedures have been clearly defined and practiced for decades. Feminist organizing has struggled with relative powerlessness as feminist organizations often lack the links to powerful figures in society and simply do not have resources or incentives to return to funding agencies (Acker, 1995).

The value of "personal as political" is present in feminist organizing (Beck & Eichler, 2000). There is a consciousness-raising element in feminist organizing which "aims to raise people's awareness of how their actions are interrelated with the structural conditions of society" (Bradshaw et al., 1994, p.29). Women-centered organizing has brought issues which were once considered private troubles (e.g. violence against women, postpartum depression, female sexual health) to the public sphere as public issues which merit attention and action (Stall & Stoecker, 1998).

Self-help movement

> When people feel themselves abandoned or frustrated by conventional society, they can sometimes bypass established institutions and create informal organizations on the side. Such grassroots movements serve to provide otherwise unavailable services, to protest indignities, to escape suffering, to relieve tension, to explain confusing events, or in some way to create a more tolerable life than is afforded by existing formal organizations (Reinelt, 1990, p. 95).

During the past several decades, self-help groups have become one of the fastest growing social trends and now occupy a significant role in health care provision (Katz & Bender, 1990; Romeder, 1990). In fact, an estimated 85 to 90 percent of all American health care is supplied by the general population to themselves and each other (Katz & Bender, 1990). "From their inception in the 1930s, the number of mutual aid groups has grown to over 500, 000 (15 million people) and cover virtually every disease or disability included in the International Classification of Diseases" (Katz & Bender, 1990, p. 127). Self-help was traditionally represented as mutual aid groups such as Alcoholics Anonymous but has since diversified to include the provision of multiple services including social support, advocacy, education, and efforts in social and political change (Powell, 1994). Self-help units include individuals, groups, communities, and nations. There is an emphasis on empowerment or promotion of inner strength and resources, self-determination, self-reliance, and self-production (Riessman & Carroll, 1995).

The self-help movement is characterized by values such as mutual aid/joint care; improved quality of life; emphasis on knowledge gained from experience; non-competitive, cooperative orientation; an anti-bureaucratic focus; a shared and circulating leadership; a belief that helping is not a commodity to be bought or sold; and optimism regarding change (Katz & Bender, 1990). Riessman & Carroll (1995) identify a variety of reasons for the success of self-help organizations including: (1) emotional support; (2) shared experience; (3) disclosure; (4) learning of coping skills; (5) normalization; (6) installation of hope; (7) cognitive restructuring; (8) empathy; (9) feedback; (10) reflection; (11) modeling; (12) self-actualization.

According to Romeder (1990), self-help groups respond to two serious individual needs: (1) the need for help in dealing with a crisis or serious difficulty; (2) the need for personal independence and autonomy (p. 3). People in such situations need to know they are not alone and that support is available. Self-help groups provide support through mutual sharing of individuals in distress with group participants who have overcome difficulties. Their shared experience allows them to feel they belong to a community of people who understand and care. Self-help groups allow participants to feel in control of their own lives. This sense of control is valued in the day and age of large institutions and bureaucracies. Health and psychosocial services, provided by government and professionals, are criticized by many as excessively rigid, inadequate, impersonal, and expensive (Romeder, 1990). Health services typically focus on the physical or technical dimensions of a condition or problem while self-help groups concentrate on the psychological, emotional, existential, and social dimensions (Borman, Borck, Hess, & Pasquale, 1982). Self-help groups, therefore, represent alternative, consumer-centered service focused on aprofessional themes such as “the concrete, the subjective, the experiential, and the intuitive” (Adams, 1990, p. 17).

The essence of the self-help movement is its ability to permit “people to convert their needs and problems into assets” and “individuals become, as it were, living resources and are ideally positioned to convert their knowledge into a potent force for guiding – and changing – other people who suffer from similar difficulties. In this way, the problem becomes part of the solution"(Riessman & Carroll, 1995, p. 22). The central themes of therapeutic self-help are, therefore, being helped through helping and the knowledge that you are not alone. The goals of therapeutic self-help organizations are to alleviate physical or psychological stress and the "promotion of personal adaptation and growth in relation to it" (Katz & Bender, 1990, p. 30). In contrast, social advocacy/action self-help organizations focus on the change or reform of social policies. These differences in orientation assist in the classification of self-help groups but do not mean that all organizations/groups fall easily into one category or the other. In many cases, there is overlap of goals/objectives with self-help organizations assuming multiple roles and broadening their mandate.

Services of national self-help organizations include provision of resources such as: literature/knowledge, newsletters, training, and conferences and workshops. "Local self-help groups affiliated with national self-help organizations offer members greater benefits because of their highly developed programs, accumulated experience, and the input of a supportive organizational network" (Wituk, Shepherd, Warren, & Meissen, 2002, p. 351). Self-help allows the target population to have "a greater say in the nature and delivery of their services" (Adams, 1990, p. 131). Success and longevity is dependent upon active commitment of individuals at every level and the diversification of leadership responsibility (Wituk et al., 2002).

Women's self-help movement

The development of women's self-help groups played an integral role in the growth of the women's movement. Self-help groups arose to assist women in challenging an institutional definition of the lives and roles of women (Gartner, 1990). According to Gartner (1990) "...one of the most important expressions of self-help is found in the feminist perspective" (p.36). There is a great deal of overlap in the values of feminist organizing and self-help organizations. Shared concepts include an empowerment approach, value in the subjective and intuitive experiences, a cooperative orientation, anti-bureaucratic focus, advocacy, and social and political change.

Self-help groups were particularly strong in the area of female health in the 1970s and '80s (MacNair, Fowler, & Harris, 2000). Hundreds, or even thousands, of loosely structured feminist groups developed at this time and functioned from a self-help framework. This trend arose from the feminist critique of the male-dominated medical world. Women responded to the feminist recognition and validation of gender inequality in treatment of the physical and emotional health of women (Taylor, 1999). "Health self-help groups and clinics arose to alleviate the sense of helplessness and powerlessness women experienced in coming to grips with issues of sexuality, body image, mental health medication, medical practices, and the sexist hierarchy of the health system" (Gartner, 1990, p. 35). Self-help health care directed attention to the education, consciousness-raising, and empowerment of the female consumer (MacNair et al., 2000).

The foundation of women's self-help groups was the simple idea that health-related knowledge was not a mystery nor was it the sole property of health professionals. Health information was available to all who wanted it (Gartner, 1990). Such groups "seek to restore women's sense of autonomy over their lives, to restore their self-reliance, and lessen their dependency on institutions that define the lives of women" (Gartner, 1990, p. 35) .Value, support, and mutual benefit was found in the act of sharing experiences with others sharing a health condition. Self-help groups reduced the isolation of and effects of stress on women coping with health-related issues. The focus is on an ethic of care rather than a cure (Gartner, 1990).

Case Study: Postpartum Depression Self-Help Movement

The following case study is presented as an example of national, feminist organizing. I believe that much can be learned from both the successes and failures of other similar organizations and, therefore, it seems useful to consider this evolution of two local support groups into known national organizations and a self-help movement in the United States. In the mid-1980s, two separate groups - Depression After Delivery (D.A.D.) and Postpartum Support International (PSI) - were formed in Pennsylvania and California by women who suffered from postpartum psychiatric illness and could not find resources on or treatment of their condition (Taylor, 1999). These two groups developed into separate but interacting national social movement organizations following an appearance by the founder of D.A.D. on the "Phil Donahue Show." Extensive media attention followed and helped D.A.D. grow to over 250 support groups nation-wide. "The movement operates through a warm line that links women with support groups, national and regional conferences, newsletters and publications, and a network of lay and professional leaders and experts whose perspective on postpartum illness is sanctioned by the movement" (Taylor, 1999, p.12).

The three central strategies of the postpartum movement included direct service, consciousness-raising, and lobbying (Taylor, 1999). Direct service is available in face-to-face support groups as well as through indirect avenues such as telephone support, self-help books and publications, talk shows/media, and pen-pal networks (Taylor, 1999). Women find shared experience, support, and community through these multiple service channels. Consciousness-raising is achieved through the provision of "preventative education to populations at risk and educating medical, mental health, and legal professionals, as well as politicians and the public at large about the needs of the women and their families" (Taylor, 1999, p. 13). Postpartum activists engage in "pressuring medical and mental health professionals to treat postpartum illness as a legitimate psychiatric disorder; lobbying for legal recognition of a postpartum psychiatric defense in cases when women are charged with killing their children; demanding health insurance coverage for postpartum illness as a complication of pregnancy; and advocating new experimental treatments, such as progesterone treatment and the use of antidepressants in pregnant and nursing women" (Taylor, 1999, p.13).

Chapter 4 - Method

Research Objectives

General research objective:

To determine if Canadians with alopecia areata and their families perceive there is a need for the creation of an organization providing support and services to them in Canada. This objective will be fulfilled by surveying Canadians with alopecia areata and their families to determine if they would prefer to use specifically Canadian resources.

Specific research objectives:

1. To survey Canadians with alopecia areata and their family members to determine if they perceive a need for a national organization and what services, if any, they require.
2. If there is a perceived need, to determine what Canadians with alopecia areata and their family members believe the objectives of a national organization should be and what role they would like to see such an organization take.
3. If there is a perceived need, to determine how Canadians with alopecia areata and their family members would like to see services of a national organization be delivered, i.e. via internet, phone information lines, newsletters, brochures, and educational materials, support groups, annual conference etc.
4. If there is a perceived need, to determine how services might be funded.
5. To determine if there are differences in perception of need for a national organization in Canada by: province of residence, age, sex, type of alopecia areata, and whether family member or person with alopecia.

Methodology

It is challenging to place the methods of this thesis project neatly into the categorical descriptors of social science research. I opted to employ various concepts from different models of social research in my study. My thesis is an exploratory study to *determine* if *need* exists among Canadians with alopecia areata for the creation of a national organization of representation. While my research objectives may deviate from the typical standards of a needs assessment, I feel that this label is the best fit for both my research objectives and design, as outlined below.

I believe the objectives of my research mirror the six reasons for conducting a needs assessment outlined by Royce, Thyer, Padgett, & Logan (2001, p. 53):

1. To determine if an intervention exists in a community.
2. To determine if there are enough clients with a particular problem to justify creating a new program.
3. To determine if existing interventions are known to or are acceptable to potential clients.
4. To determine what barriers prevent clients from accessing existing services.
5. To document the existence of an ongoing/exacerbating social problem.
6. To obtain information for tailoring a program to a specific target population.

A needs assessment collects information to aid service providers in meeting the needs of a community or population (McKillip, 1987; Royse et al., 2001). This type of research is known as "applied" with the outcome informing decisions/practices regarding service. This model is generally used when concern exists that services to an identified population/community are unsatisfactory (Royse et al., 2001). A needs assessment may also be known as a feasibility study. It is the first step in program evaluation as need for a service or program must be determined prior to its inception (Royse et al., 2001).

Funding for social services is scarce and competition is fierce, therefore need must be justified. Beyond determination of need, these studies may also provide important information about the target population as well as provide guidance in program mobilization and planning (McKillip, 1987; Royse et al., 2001).

I conducted an informal resource inventory on the target population of Canadians with alopecia areata (see p 13) through the internet and discussions with the National Alopecia Areata Foundation in the U.S. and Canadian alopecia areata support group leaders. It was clear that there was a lack of specialized service for this community. My research objectives evolved from both my own personal experience as a Canadian with alopecia areata and my conversations/interactions with other Canadians coping with this disorder.

Empowerment

As a student of social work, I work from an empowerment value orientation or a strengths perspective. The objectives of an empowerment approach to research include identifying participant strengths and enhancing wellness (Zimmerman, 2000). Social change is accomplished by focusing on health, adaptation, competence, and natural helping systems rather than risk factors, fixing "problems", or blaming victims (Zimmerman, 2000). Empowerment is the commitment to and process of helping people to discover, expand, and use the strengths within and the resources around them (Saleebey, 2002).

Feminist research

There is not a single defined way to employ a feminist methodology (DeVault, 1996). Taylor (1999) states "The goal of feminist research is to make women's experiences visible, render them important, and use them to correct distortions from previous empirical research and theoretical assumptions that fail to recognize the centrality of gender to social life" (p.11). Feminist research recognizes the subjectivity of the researcher and suggests "making the researcher visible in any product of research" (DeVault, 1996, p.9). The feminist researcher is encouraged to view the self as a resource rather than something that must be denied or controlled. As a feminist and an individual with alopecia areata, this research process was, in many ways, a very personal journey. My subjective experience could not be contained. A feminist methodology allowed me to conduct this research through a gendered lens and maintain my place within the research process. I subscribed to principles of a feminist methodology in my focus on gender and gender inequality, in seeking the voice of women, in valuing the subjective experience, in my effort to incorporate participatory methods, in proposing change in the lives of this population of women, in my link to activism, and in my commitment to determining the needs of an invisible community. All of these practices evolved from the goals of feminist research described below.

DeVault (1996) attributes a feminist methodology to research with the following three goals. First, feminists employ a methodology that allows them to "excavate" or "reveal both the diversity of actual women's lives and the ideological mechanisms that have made so many of those lives invisible" (DeVault, 1996, p.3). Second, feminists use methods/practices in research that "minimize harm to women and limit negative consequences" (DeVault, 1996, p.4). Third, feminists use methods that allow them to conduct research that is of value to women and has "relevance to change in women's lives or in the systems of social organization that control women" (DeVault, 1996, p.4).

Perhaps the biggest debate in feminist research is the division, value, and assumptions of qualitative and quantitative approaches. Many feminists believe that qualitative methods are more effective at realizing feminist goals (DeVault, 1996). Qualitative methods have often been used in the collection of personal testimony of individuals and has been a valuable method to "make visible" the experiences of women. It is important, however, to note that many feminists view quantitative techniques as a compelling strategy to find the voices of women. Quantitative research involves interpretation. Feminist researchers may interject feminist values in a quantitative research design and employ a feminist framework in the interpretation of findings (DeVault, 1996). "Many feminists advocate combining quantitative and qualitative tools" (Devault, 1996, p. 6).

Research Design

Central to the objectives of this needs assessment is the exploration of *felt* need within the population of Canadians with alopecia areata and their family members. An exploratory research design was employed as this approach is useful in the examination of a relatively new subject of study (Babbie, 2001). This population has not been studied to determine need for service in this country. Canadians with alopecia areata have become enmeshed with their US counterparts and thus, have not had an opportunity to voice their unique needs for service. The intent of the current research design is to give voice to them.

The focus of this needs assessment is primarily on quantitative data in determining need for a new service. This study does not have an independent and dependent variable and is not focused on causality since its purpose is descriptive.

However, several open ended questions have the possibility of yielding valuable qualitative data in the form of opinions and suggestions about whether a Canadian Association is needed and how it should be structured. A mixed method was, therefore, employed to incorporate both the objective and subjective components of the social realities of this community (Brewer & Hunter, 1989).

Definitions

The following definitions clarify who was eligible to participate in this study and the type of needs which were addressed in the survey tool:

Felt Need – "perceptions of need as ascertained by consulting actual clients" and is collected by surveying clients, traditionally by mail (Royse et al., 2001, p.53). In this case, needs expressed by the target population of Canadians with alopecia areata and their family members.

Family members – parents or siblings of children with alopecia areata and spouses of individuals with alopecia areata.

Canadians with alopecia areata – individuals over the age of 16 years who self-identify as Canadians and as having alopecia areata.

Sampling

Nonprobability sampling was used in this study as there was no existent list or database of all individuals with alopecia areata in Canada. This eliminated the feasibility of random assignment/selection. Purposive sampling is a type of nonprobability sampling method used when studying "a small subset of a larger population in which many members of the subset are easily identified, but the enumeration of all of them would be nearly impossible" (Babbie, 1989, p. 204). In this method, the researcher's knowledge of the population and its elements are consulted according to the goals of the research. It is important to recognize that nonprobability sampling is an unreliable indicator of representativeness and thus is best suited to exploratory studies (Babbie, 2001).

I contacted the National Alopecia Areata Foundation in the United States regarding my research and they generously sent an e-mail invitation (See Appendix B) with a link to my web site to all the Canadian members listed in their database on March 16, 2004. Four of the Canadian support group leaders affiliated with the National Alopecia Areata Foundation were contacted via e-mail to inform them of this study. I contacted the manager/founder of the Alopecia Areata Support Community, an international internet forum for individuals with alopecia areata and requested assistance in reaching individuals with alopecia areata. My e-mail invitation (See Appendix B) was posted on the message board of the web site for this support community (www.alopeciaareata.resourcez.com) and was also sent out via e-mail to all of the members of this community on March 22, 2004 (the manager was unable to send the e-mail to Canadians only). In addition, an information flyer was posted on the bulletin board in the waiting room of a local dermatologist.

My feminist values and empowerment orientation informed my decision to identify myself as a Canadian with alopecia areata in the e-mail invitation sent out to potential participants. The following was stated in the participation invitation: "Personal experience with alopecia totalis and universalis for the past 20 years has inspired and driven my current research objectives." I felt it was important to locate myself within the community under study and communicate broad reasoning for my research objectives. It was my intention to encourage participants to view me as a "collaborator" rather than an "expert" and join with me in this process.

Data Collection

A survey was deemed to be the most appropriate and cost-effective tool to determine the general opinion of individuals with alopecia areata across Canada. Surveys are employed by many sectors of society and are generally familiar to most people (Royse et al., 2001). They are a useful method to collect data when observation is not feasible and they are considered to be "excellent vehicles for measuring attitudes and orientations in a large population" (Babbie, 2001, p. 238). In addition to evaluating attitudes and opinions, surveys may also yield valuable information regarding behaviours and population characteristics (McKillip, 1987). Surveys are considered to be the most precise and scientific method of data collection for use in a needs assessment (Royse et al., 2001). It is important, however, to recognize that surveys are reactive and may create expectation that a program or an organization will be formed (McKillip, 1987). Clarity of intent, therefore, has heightened value in this case.

The intent of this survey is to determine if Canadians with alopecia and their family members perceive a need for a national organization in Canada; what the objectives of such an organization should be, how services of a national organization should be delivered and funded; and if there are differences in perception of need for a national organization by province of residence, age, sex, type of alopecia areata, age of onset, and whether family member or individual with alopecia areata.

Large-scale community surveys are costly and time-consuming (Royse et al., 2001). The age of technology allowed me to minimize both the labor and cost associated with surveying individuals across the country. A self-administered web-based questionnaire employing both open-ended and close-ended questions was used as the data collection tool in this study (See Appendix A). Globally, people with alopecia areata have overcome physical barriers to support and information through the use of the internet. It seemed natural to use the vast capabilities of the internet to reach my target population.

The process of designing and launching a web-based survey required technological assistance and adequate time for test runs of the database connection. I designed both the information letter/consent form and the survey in Microsoft Word format. The survey was coded for internet application, and two databases were constructed for direct data entry. Following a test of the databases, the survey was launched on the social work web page. The survey was hosted at the following web address: http://www.wlu.ca/fsw/thesis_bonnie_lipton/index.html. This web site was launched on March 14, 2004. A link to this web address was hosted on the Faculty of Social Work web page under the heading *Affiliated Research Projects.* The survey and database were designed to detect the IP address of the participant in order to prevent a participant from completing the survey more than once from the same computer and internet connection. It is however, possible that a participant could complete the survey a second time from a computer with a different IP address.

Data Analysis

The use of a mixed method required the employment of both quantitative and qualitative analysis techniques. In quantitative analysis there are three factors to consider: "(1) The number of variables being examined; (2) The level of measurement of the variables; (3) Whether we want to use our data for descriptive or inferential purposes" (de Vaus, 1987, p. 97). In this case, quantitative data will primarily be descriptive in nature. Descriptive statistics aim to discover patterns and thus are appropriate in this case. Cross-tabulations were preformed to determine the presence or absence of relationships between gender, location (province), type/degree of alopecia areata, age, and perception of need for the formation of a national organization for Canadians with alopecia areata. Comparison of means was used to analyze this data, when appropriate.

Qualitative data analysis was completed according to concepts and techniques outlined by Strauss and Corbin (1998) and Tutty, Rothery, and Grinnell (1996). Central to this process was active reflection on the material presented in the open-ended questions. Conceptualization of responses was initiated through the task of *first-level* or *open* coding. Each question was coded separately. I read all the responses to one question and underlined concepts which struck me as interesting or relevant to the posed question. Similarities and differences in responses were noted through the use of letter labels (e.g., a G was placed next to any response that referred to geography/location). A running list of letter labels/open codes was kept throughout first level analysis of each question. Any "in vivo" codes which emerged from the data were highlighted in yellow. This stage of the analysis was straightforward and predominantly descriptive in nature.

Once each question was open-coded, I proceeded to code across questions in order to identify related ideas or phenomena. This stage of analysis may be referred to as *second-level* or *axial* coding. Axial coding involves "relating categories to subcategories along the lines of their properties and dimensions" (Strauss and Corbin, 1998, p. 124). Letter-labeled concepts were grouped into categories according to shared dimensions.

Each category was assigned a name and a colour for identification (e.g., codes falling under the category of isolation were highlighted in pink). At this stage of the analysis, I found myself caught up in the emotion, stories, values, and beliefs expressed throughout the text. I was very cautious at this point to keep a journal of my personal experiences and emotions related to the data as it was both personally relevant and emotionally compelling given my status as a member of the population community. I reviewed my coding process by reading through my open codes and axial codes twice, consulting my journal to separate my personal responses to the data from my analytical reflections on the data.

Finally, categories identified through axial coding were assessed for connections which I used to integrate the research phenomena into a central theme. This is what Strauss and Corbin (1998) term *selective coding* and Tutty et al. (1996) identify as the "formal" step of *interpreting data and elaborating upon themes.* At this stage of analysis, I was particularly sensitive to the tone of the responses and capturing the meaning within and between codes and categories.

The qualitative process allowed me the opportunity to become more intimately acquainted with the experience of the participants and the humanity present in the data. In the coding the data, I was vigilant in separating my experiences with alopecia areata from that of my participants. I struggled to be aware of my values and biases which had the potential to intervene in my conceptualization of the responses. As I became emerged in the qualitative data, the data spoke to me both as a researcher and as a woman with alopecia areata. It was not difficult to find meaning in the text; my goal was to remain true to what the data was saying.

Ethical Considerations

In conducting an ethics review, several factors must be considered. Participation in research must be voluntary and have free and informed consent (Babbie, 2001). In this case, participants were free to either complete the questionnaire or not and were not required to answer questions if they did not want to. Participants were instructed to exit their web browser at any point to safely discontinue participation. An informed consent letter preceded the survey to outline confidentiality of personal information. In order to gain access to the survey on the web-page, participants were required to indicate "I agree" to participate, given the provided information on confidentiality. The release of contact information was voluntary and was not requested until participants completed the survey. Survey data transferred directly into a secure database that was accessible only to myself, my thesis supervisor, and one technological assistant. Participants were informed that their questionnaires would be kept separate from Contact Information Forms and identifying information would not be released to third parties. The Contact Information Form was included in this project in order to start a list of Canadians with alopecia areata who would like to be involved in the creation of a national organization. I felt that this research as a good opportunity to connect with Canadians with alopecia areata and collect much needed human resources for such an endeavor. Participants were informed in the study information letter that confidentiality of information could not be ensured while data was in transit in the internet.

There were no identified risks to the participants in this study and deception was not employed in this research. One concern, however, was present in conducting this research. The possibility existed that Canadians with alopecia areata may misinterpret the power of this survey and expect immediate action in creating a national organization in Canada. Participants may fail to understand the *exploratory* nature of this project. This risk was controlled by clear statement of the purpose and nature of the research in the study information letter.

I reviewed the Canadian Association of Social Workers' Code of Ethics and the Tri-Council Guidelines and ensured that my research was conducted according to these values. The research plan was approved by the Research Ethics Board at Wilfrid Laurier University. Participants were informed in the information letter that they will be able to access results of the study and feedback on the website set up to collect data, and will receive a hard copy if requested in the Contact Information Form.

Limitations

There are clear limitations to the current study. First and foremost, I cannot confidently generalize the findings of this research beyond my sample. However, the strength of the support (93%) for the development of a national association in the sample size (134) is suggestive of significant need for a Canadian Alopecia Areata Association. This could however, be a self-selecting population of supporters for increased service and therefore, may not be representative of the population.

I believe it is important to address the fact that as a woman with alopecia areata, I am a member of the target research population. While I outlined the potential benefits of this location in the body of this thesis, there all possible risks and, in particular, personal biases, that may have impacted this study. It is obvious that my social location as a member of the Canadian alopecia areata community prevented me from maintaining a pure objective stance in analysis of the qualitative data. I made every effort to be cognizant of potential biases I may have harboured or developed during data analysis by discussing my feelings and reactions with my thesis supervisor and my peers in social work. The data collection and analysis phase of this project proved to be very difficult for me. I sought professional assistance in coping with my own personal reactions to the data and I used this forum on a weekly basis to process my emotions. It is, however, possible that my data analysis or my interpretation of results may have been coloured by personal biases as follows: (1) I entered into this research project with the expectation that the need for a Canadian Alopecia Areata Association would be determined to be present, (2) I was biased in my focus on the experience of women with alopecia areata, and (3) I carry a certain degree of frustration with the lack of services available to me in Canada.

Due to ethical restrictions on the study of children, this survey was directed to Canadians over the age of 16 years. It is clear from the results that a large number of Canadians with alopecia areata develop the condition prior to the age of 20 years; therefore, it is clear that this study neglected to directly obtain the voice or address the needs of Canadian children and youth coping with alopecia areata. The needs of children were expressed by parents in this study but it would have been interesting to hear what the children and youth of Canada had to say about alopecia areata. I believe a needs assessment directed to children and youth with alopecia areata would enrich the findings of the current study.

It is important to note that the current sample may not be representative of all Canadians with alopecia areata for the following reasons. A large number of participants were familiar with the National Alopecia Areata Foundation (NAAF) in the United States with 40% currently accessing some form of service from this organization. Indeed, NAAF sent a mass e-mail invitation to this study to its Canadian members and it is possible that a large portion of the current sample was drawn from this pool. In addition, as mentioned in the methodology, the current study was limited to English Canada as the survey tool was not available in French. It is impossible, therefore, to generalize these results to Francophone Canadians, most notably in the province of Quebec.

Finally, the most obvious limitation to this study was the method in which data was collected – via the internet. Participation was therefore limited to Canadians who had access to both a computer and an internet connection. The internet survey therefore would have failed to reach those who do not have easy and inexpensive access to computers, such as those who cannot afford a home computer or who have not learned to use internet services.

Chapter 5 – Results

Introduction

Congruent with the exploratory nature of this study, data analysis was primarily descriptive. Crosstabulations were conducted in order to assess the presence of patterns/trends between population demographics and the main research question. The presentation of quantitative and qualitative results are organized following the format of the survey tool: (1) population demographics, (2) experience with alopecia areata, (3) domestic and international support services, (4) unmet needs, (5) need for a Canadian alopecia areata association, and (6) perceived challenges. Finally, an additional section titled "Overall themes" is included to encapsulate the general ideas which emerged from qualitative analysis of all open-ended questions. This section allows an understanding of the experience and expressed needs of Canadians contending, in some capacity, with alopecia areata.

Population Demographics

In total, 134 Canadians responded to the online survey. Females represented 73.9% (99) of the participants while 26.1% (35) of the sample was composed of male participants. All of the given age ranges were represented by both sexes. The distribution of age and gender were compared to see if there was a difference in age between male and female participants (see table 1). No statistically significant relationship was reported between gender and age as demonstrated by chi-square ($x^2 = 7.82$ (5), $p = 0.166$). More than half of the females (58.2% - 57) reported being between the ages of 20 and 39 years while the majority of males reported being under the age 20 years (28.6% - 10) and between the ages of 30 to 39 years (25.7% - 9).

Table 1.

Gender and Age

	Age in years					
Gender	**Under 20**	**Between 20-29**	**Between 30-39**	**Between 40-49**	**50 +**	**Total**
Males	28.6% (10)	17.1% (6)	25.7% (9)	20.0% (7)	8.6% (3)	26.3% (35)
Females	11.2% (11)	32.7% (32)	25.5% (25)	18.4% (18)	12.2% (12)	73.7% (98)
Total	15.7% (21)	28.6% (34)	25.6% (34)	11.3% (15)	11.3% (15)	133

As expected, the province of Ontario had the highest representation with 50.4% (67) of the participants. British Columbia and Alberta followed, each with 12.0% (16) of the sample and Quebec obtained 10.5% (14) of the participants. Both the Prairies and the Maritimes had little representation (see table 2). There were no participants from the three territories.

Table 2.

Province

BC	**AB**	**SK**	**MB**	**ON**	**QC**	**NB**	**NS**	**PE**	**NF**	**TR**	**Total**
12.0% (16)	12.0% (16)	2.3% (3)	2.3% (3)	50.4% (67)	10.5% (14)	2.3% (3)	1.5% (2)	3.8% (5)	3.0% (4)	0% (0)	133

Experience with alopecia areata

Descriptive information was collected regarding participants' experience with alopecia areata. Of 134 participants, 83.6% (112) reported that they had alopecia areata. The remaining 22 participants indicated they were family members of a person with alopecia areata. Age of onset varied among the 112 participants with alopecia areata from one year to 60 years, with 41.1% (46) developing alopecia areata at the age of 12 years or younger, 26.8% (30) between the ages of 13 and19 years, and 32.1% (36) over the age of 20 years. These results are consistent with previous research which indicates the majority of individuals with alopecia areata develop the condition during childhood.

Almost half (48.2% - 54) of the 112 participants reported losing all (100%) of their scalp hair (see table 3). Of 85 participants, 64.7% indicated that they had lost body hair as well. 40.0% of 103 participants reported that their nails were also affected by alopecia areata. As alopecia areata is an unpredictable condition with hair loss fluctuating in severity and changing over time, participants were asked to report how many episodes of alopecia areata, totalis, and/or universalis they had experienced (see table 4).

Table 3.

Greatest Amount of Hair Loss on Scalp

None	Up to 25%	26–50%	51-75%	76-99%	100%	Total
0.0% (0)	16.1% (18)	16.1% (18)	8.9% (10)	10.7% (12)	48.2% (54)	112

Table 4.

Number of Episodes of Alopecia Areata, Totalis, Universalis

Only 1 (including continous)	2 – 5	6 – 10	> 10	Too many to count	Don't know	Total
41.1% (46)	30.4% (34)	6.3% (7)	0.00% (0)	14.3% (16)	6.3% (7)	112

Domestic and international support services

Participants were asked to indicate where they received information on support services at the time of their/their child's diagnosis of alopecia areata (see table 5). The majority of participants reported receiving information from the National Alopecia Areata Foundation (30.4% - 38) or their dermatologist (29.6% - 37). Many of the participants who used the internet at time of diagnosis (15.2% - 19) specified using the *Google* search engine to locate web sites on alopecia areata. One person reported using the web site keratin.com and one person indicated using the NAAF web site. Of the 125 participants to this question, 17.6% (22) indicated *other* sources. Several indicated that they did not receive any recommendations for support services and/or found there were no local resources available. Friends, local support groups, a naturopath, and a wig manufacturer were also indicated as sources of information on support services.

Table 5.

Where Support Information was Accessed Following a Diagnosis of Alopecia Areata

Family Physician	Dermatologist	National Alopecia Areata Foundation	Internet	Other	Total
7.2% (9)	29.6% (37)	30.4% (38)	15.2% (19)	17.6% (22)	125

When asked to comment on the strengths of Canadian services for individuals with alopecia areata, an overwhelming majority of participants used this space to express the weaknesses of services for them in this country. These responses, therefore, were included in the section addressing unmet needs. The few strengths indicated by participants included Dr. Shapiro's clinic for hair loss at the University of British

Columbia, Sunnybrook and Women's College Hospital in Toronto, and a few participants reported that their family physician and/or dermatologist provided them with information and support.

> Sunnybrook and Women's College Hospital have a wonderful team of specialists and residents that are supportive and empathetic.
>
> We are fortunate to be so near Dr. Jerry Shapiro and his clinic.
>
> Only Canadian services accessed were other Alopecians – who by the way – were wonderful! Also felt reassured that if my daughter's Alopecia came to a point that she wanted to pursue treatment that we have Dr. Shapiro in BC.

Of the 134 participants, 60% (75) reported that they are currently accessing support services (see table 3). Under half of all the participants (40% - 30) indicated the National Alopecia Areata Foundation as their current support provider. The internet was reported as the current support provider for 25.3% (19) of the participants and 14.7% (11) are able to access a local support group for alopecia areata.

Table 6.

Current Support Provider

Health Provider	Internet	Local Support Group for AA	Mental Health Provider	National Alopecia Areata Foundation	Phone Support Line for AA	Other	Total
12.0% (9)	25.3% (19)	14.7% (11)	4.0% (3)	40.0% (30)	1.3% (1)	2.7% (2)	75

It is apparent that a large number of participants have, at some point, accessed services from the National Alopecia Areata Foundation (NAAF) in the United States. Of the 134 participants, 70.1% (106) reported that they are a member of NAAF and 41.0% (55) indicated that they have used services provided by NAAF. Participants commented on the strengths of NAAF services to them as Canadians. Many participants specified print materials including an information package, information brochures, newsletters, and an information package for a school setting.

> Most of what I know of the condition was learned through NAAF and their services. They are knowledgeable and extremely supportive of what you are going through and take their time to give information and support to you and your family.
>
> I felt I had received information on the up to the minute research on alopecia and felt the information was very trustworthy.
>
> The information mailed to me was much more informative than the doctors.

Others indicated use of the NAAF website and their e-mail pen pal program. Finally, a number of participants reported that attending the annual NAAF patient conference to be very helpful, as face-to-face support was invaluable.

> The conferences are wonderful and so uplifting.
>
> I have been with my son – who has AU – to one NAAF conference and would love to be able to take him to more.

Unmet needs

Participants were asked what needs, as a Canadian with alopecia areata, were not met through accessing services through NAAF. Several participants reported that the financial cost of travel prohibits them from attending the annual NAAF conference. Others indicated that NAAF is unable to advocate to Canadian insurance providers or promote public awareness of the condition in Canada. The overall tone of the responses was that the NAAF services are good but obvious limitations exist because they represent the United States, not Canada.

> The services are very good and they are very helpful but all of these services are located in the U.S. I have not found many things that were available in Canada.
>
> NAAF is a very good organization but a Canadian organization could address the aspects that touch us as Canadians. It does not need to replace NAAF.

Qualitative analysis of the weaknesses of services in Canada exposed a number of unmet needs. Responses are organized under the following categories: absence of support services and knowledgeable professionals, and physical and emotional isolation. Many participants reported that there are no services available to Canadians with alopecia areata beyond basic medical care. A number of participants indicated that their family physician and/or dermatologist was unable to provide them with any information on the disorder or support services. Several Canadians with alopecia areata expressed disappointment in the services of medical professionals as they felt their emotional distress and fears at the time of diagnosis were dismissed. Participants expressed frustration with the lack of information and services available to them in Canada and many responded that they feel alone in coping with this condition.

> I think most of the pertinent information we can get comes to us via the US. It is a real weakness here in Canada.
>
> There just aren't any support groups! I have been online to the NAAF (US) – which is great – but there's nothing in Canada beyond medical care.
>
> I was given the diagnosis and told there was not much could be done. I looked for answers on my own.
>
> My son is only 5 years old and this is his second episode of Alopecia Areata. Our dermatologist's comment was his hair grew

> back last time it will again and sent us home. No support. No information. It has been four months, it is worse not better.
>
> There is no services. Even our dermatologist didn't know what kind of medication or help to give my daughter. We finally got the most information at our hair cutter.
>
> Nobody knows what it is. There are absolutely no Canadian services. My dermatologist did not even recommend or inform me of where to get support.
>
> It is very difficult to get information in Canada. Most websites are outside Canada. There is no written information provided by our dermatologist or our family doctor.
>
> I find that the doctors are not up to the current speed of the disease. I saw several doctors and only one knew what I had. All the other doctors thought it was stress and put me on antidepressants.

Canadians reported struggling with both physical and emotional isolation in accessing services and coping with alopecia areata. Many Canadians with alopecia areata indicated that they have to travel from their home to seek basic medical treatment for their condition and to find products such as hair pieces to assist in coping with their hair loss. Participants responded that locating any services is difficult, especially if they do not live in a large urban center.

> I have to travel 3 hours once a month to get treatment.
>
> I have had to travel 5.5 hours away to Toronto to get any kind of treatment or advice.
>
> The set up of adequate regional and/or national support groups. There is also an unbelievable sense of isolation here for me in the National Capital region.
>
> There are support groups in Vancouver and Vancouver Island but nothing supported in Northern BC.

Indeed, more than three quarters (77.5% - 100) of 129 participants reported that they do not feel they have adequate access to information and support for alopecia areata by providers in Canada. A crosstabulation was run between gender and perception of access to support and information for alopecia areata in Canada to see if there were any differences between the perception of males and females (see table 7). As noted in the introduction, I hypothesized that women would feel there was a greater need for service. No statistically significant difference ($x^2 = 0.705$ (4), $p = 0.951$) was found.

Table 7.

Gender and Perception of Access to Support and Information for Alopecia Areata in Canada

	Perception of Canadian service					
Gender	**(1) Completely Inadequate**	**(2)**	**(3)**	**(4)**	**(5) Completely Adequate**	**Total**
Female	47.9% (46)	31.3% (30)	15.6% (15)	3.1% (3)	2.1% (2)	96
Male	45.5% (15)	27.3% (9)	21.2% (7)	3.0% (1)	3.0% (1)	33
Total	47.3% (61)	30.2% (39)	17.1% (22)	3.1% (4)	2.3% (3)	129

Need for a Canadian alopecia areata association

This section addresses the main objective of this study: to determine if Canadians with alopecia areata and their families perceive there is a need for the creation of an organization providing support and services to them in Canada. One hundred and eight (83.1%) of the 130 participants who responded to this question indicated that they strongly agree there is a need for a national alopecia areata foundation in Canada.

Several crosstabulations were preformed to determine if there are differences in perception of need for a national organization in Canada according to gender, province, age, type of alopecia areata, and whether family member or person with alopecia areata.

No statistically significant difference was found between gender and felt need for a Canadian alopecia areata association ($x^2 = 4.25(3)$, $p = 0.235$). Minor differences were noted between men and women and their perception of need for a Canadian association (see table 8). Of the 130 participants, 83.5% (81) of women and 81.8% (27) of men indicated that they strongly agree there is a need for a Canadian alopecia areata association. Gender does not appear to affect perception of need.

Table 8.

Gender and Felt Need for a Canadian Alopecia Areata Association

	Felt need for a Canadian alopecia areata association					
Gender	**(1) Strongly disagree there is a need**	**(2)**	**(3)**	**(4)**	**(5) Strongly agree there is a need**	**Total**
Women			5.2% (5)	11.3% (11)	83.5% (81)	97
Men		3.0% (1)	9.1% (3)	6.1% (2)	81.8% (27)	33
Total		1	8	13	107	130

(4 cells have expected count less than 5)

The relationship between province of residence and felt need for a Canadian alopecia areata association was tested using chi-square analysis. The data did not, however, meet the assumptions for the statistic because there were 39 cells (88.6%) with an expected count less than 5. It is evident from a review of Table 9 that there is little variation in responses. Participants in all provinces seemed to agree there is a strong need for the development of Canadian services for individuals with alopecia areata (see table 9). It is interesting to note that 100% of the participants from the provinces with fewer participants and more rural areas (ie. The Maritimes and Saskatchewan) reported that they strongly agree there is a need for a Canadian alopecia areata association.

Table 9.

Province and Felt Need for a Canadian Alopecia Areata Association

	Felt need for a Canadian alopecia areata association					
Province	**(1) Strongly disagree**	**(2)**	**(3)**	**(4)**	**(5) Strongly agree**	**Total**
British Columbia				6.3% (1)	93.8% (15)	16
Alberta		6.3% (1)	6.3% (1)	6.3% (1)	81.3% (13)	16
Saskatchewan					100% (3)	3
Manitoba				1	66.7% (2)	3
Ontario			7.7% (5)	13.8% (9)	78.5% (51)	65
Quebec			7.1% (1)	7.1% (1)	85.7% (12)	14
New Brunswick					100% (3)	3
Nova Scotia					100% (2)	2
Prince Edward Island					100% (4)	4
Newfoundland					100% (3)	3
Territories						0
Total	0.00% (0)	0.8% (1)	5.4% (7)	10.1% (13)	83.7% (108)	129

(39 cells have expected count less than 5)

It is clear in Table 10 that the perception of need for Canadian services is very similar among all age groups. When the chi-square analysis was run, the data did not meet the assumptions for the statistic because there were 19 cells (79.26%) with an expected count less than 5. Review of table 10 suggests that there is little variation in responses, with most participants agreeing there is a strong need. Canadians between the ages of 30 and 39 years reported the highest perception of need at 87.1% (27) while the next age group up, 40 to 49 years, reported the smallest perception of need at 76.0% (19).

Table 10.

Age and Felt Need for a Canadian Alopecia Areata Association

	Felt need for a Canadian alopecia areata association					
Age in Years	**(1) Strongly disagree there is a need**	**(2)**	**(3)**	**(4)**	**(5) Strongly agree there is a need**	**Total**
Under 20			5.0% (1)	10.0% (2)	85.0% (17)	20
Between 20-29			7.9% (3)	7.9% (3)	84.2% (32)	38
Between 30-39			3.2% (1)	9.7% (3)	87.1% (27)	31
Between 40-49			12.0% (3)	12.0% (3)	76.0% (19)	25
50 +		6.7% (1)		13.3% (2)	80.0% (12)	15
Total		1	8	13	107	129

(19 cells have expected count less than 5)

It is interesting to note that slightly more family members of Canadians with alopecia areata (85.7% - 18) than Canadians with alopecia areata (82.4% - 89) strongly agreed that there is a need for a Canadian alopecia areata association (see table 11). Once again, the variables did not meet the assumptions for the chi-square analysis because there were 8 cells (66.7%) with an expected count less than 5. The results of table 11 show that there is little variation in responses. Both individuals who have alopecia and areata and family members (individuals who do not have alopecia areata) appear to feel there is a strong need for a national organization.

Table 11.

Have Alopecia Areata and Felt Need for a Canadian Alopecia Areata Association

	Felt need for a Canadian alopecia areata association					
Have Alopecia Areata	**(1) Strongly disagree there is a need**	**(2)**	**(3)**	**(4)**	**(5) Strongly agree there is a need**	**Total**
No			4.7% (1)	9.5% (2)	85.7% (18)	21
Yes		0.9% (1)	6.5% (7)	10.2% (11)	82.4% (89)	108
Total		1	8	13	107	129

(8 cells have expected count less than 5)

Options for delivery of services were listed and participants were able to select multiple responses. All delivery options appeared relatively equal in importance to participants (see table 12). Phone information and support lines received the least number of selections while “all of the above” was selected most often (48.5% - 65), followed closely by print material such as brochures/ pamphlets and newsletters received the most selections (47.8% - 64 respectively). Support services, such as organized support groups and an annual conference, were almost as likely to be selected (45.5% - 61), and there was strong support for a children’s camp as well (42.5% - 57). Given the fact that an additional 48.5% selected “all of the above,” the results for each delivery option increase. This means that 81.3% selected a phone information and support line, 96.3% selected brochures/pamphlets, 88.8% selected internet chat rooms/message boards, 94% selected organized support groups, 94% selected annual conference, 91% selected annual children’s camp, and 96.3% selected newsletters. It is apparent that participants would like to see all of the given delivery methods employed by a national organization serving Canadians with alopecia areata.

Table 12.

Delivery of Services

Phone info and support line	Brochures/ Pamphlets	Internet chat rooms/ message boards	Organized support groups	Annual conference	Annual children's camp	News-letters	All of the above	Total
32.8% (44)	47.8% (64)	40.3% (54)	45.5% (61)	45.5% (61)	42.5% (57)	47.8% (64)	48.5% (65)	134

Participants were asked to prioritize possible objectives of an organization as *essential*, *very important*, and *may not be necessary*. The results are displayed in Table 13 with the objectives ranked from "most essential" to "least essential," according to percentage rates. Participants clearly value the provision of support to individuals with alopecia areata in Canada as the most essential objective of a Canadian alopecia areata association (80.3% - 102). More than three quarters of participants indicated information/education materials for individuals with alopecia areata (77.6% - 97) as an essential objective. Finally, over half also felt that the following objectives were essential (objectives): advocate for improved health care and insurance policies as they pertain to hair loss/alopecia areata (68.5% - 85); fund medical research on alopecia areata (68.5% - 87); provide current resource materials/ research on the status of the condition, its treatment, and the psychological impact of a diagnosis of alopecia areata to family physicians and dermatologists (67.5% - 85); network individuals with alopecia areata in Canada (63.5% - 80); promote public awareness of the condition (57.9% - 73); and fund socioemotional and psychological research on alopecia areata (51.2% - 64). All of the given objectives were selected as either essential or very important by an overwhleming majority of participants.

Table 13.

Objectives of a National Organization for Canadians with Aalopecia Areata

Objective	**Essential**	**Very Important**	**May not be necessary**	**Total**
Provide support to individuals with alopecia areata in Canada	80.3% (102)	18.1% (23)	1.6% (2)	127
Supply information/education materials for individuals with alopecia areata and family members	77.6% (97)	18.4% (23)	4.0% (5)	125
Advocate for improved health care and insurance policies as they pertain to hair loss/alopecia areata	68.5% (85)	23.4% (29)	8.1% (10)	124
Fund medical research on alopecia areata	68.5% (87)	25.2% (32)	6.3% (8)	127
Provide current resource materials/ research on the status of the condition, its treatment, and the psychological impact of a diagnosis of alopecia areata to family physicians and dermatologists	67.5% (85)	27.8% (35)	4.8% (6)	126
Network individuals with alopecia areata in Canada	63.5% (80)	30.2% (38)	6.4% (8)	126
Promote public awareness of the condition	57.9% (73)	31.0% (39)	11.1% (14)	126
Fund socioemotional and psychological research on alopecia areata	51.2% (64)	39.2% (49)	9.6% (12)	125
Provide support to family members of individuals with alopecia areata	47.2% (59)	38.4% (48)	14.4% (18)	125

One hundred and nineteen participants responded to the question of whether or not they would be willing to pay an annual membership fee to a national organization for Canadians with alopecia areata. An overwhelming majority (87.6% - 103) of these participants indicated that they were willing to pay a membership fee. Less than half of the participants (42% - 50) considered $20.00 to $25.00 a reasonable annual membership rate for one adult (see table 14). A few individuals expressed concern regarding a yearly membership as it may have the potential to alienate those who cannot afford such a fee.

A suggestion was made to make the first year of the membership free to allow members the opportunity to access the value of service.

Table 14.

Adult Membership Rate (per year)

No Charge	**$10**	**$15**	**$20**	**$25**	**$30**	**$40**	**Greater than $40**	**Total**
7.6% (9)	12.6% (15)	6.7% (8)	19.3% (23)	22.7% (27)	13.4% (16)	9.2% (11)	8.4% (10)	119

Perceived challenges

Participants were asked "What are the challenges you anticipate in setting up a national association serving Canadians with alopecia areata?" Qualitative analysis revealed the following five categories: geographical limitations, private and/or public funding, misunderstanding of alopecia areata/lack of public awareness, lack of commitment from the medical community, and volunteers (human resources). It was evident that the participants anticipated many potential challenges in initiating a Canadian organization to serve their unique needs.

Geographical limitations

The sheer size of our country was perceived by participants to be a significant barrier to connecting Canadians with alopecia areata as a united front. Participants seemed concerned that tangible support would only be available in urban areas and, therefore, would not be accessible to rural Canadians. Indeed, geography was implicated as a current barrier for Canadians with alopecia areata in their efforts to receive medical treatment and locate quality head coverings such as wigs. It is clear that participants are intimately aware of the struggles of connecting a small population across large space:

> The enormous size of our country and connecting with each other. Representation from people across the country would be best but getting everyone together in one location would be financially prohibitive. However – using people in various locations to network in their areas then connect a central team would be the next best.
>
> Space – geography – Southern Ontario is dense but what about Manitoba – for instance. Hard to gather people for a physical meeting.
>
> Small population spread out over a large area. May have to limit much of the support to urban centres.
>
> One thing not mentioned is the ability to network and help those who suffer the condition easily locate services in their community that could potentially help mask the condition...providers of wigs etc. – that type of the things. It has been a challenge living in a community that does not have these services – where most people are unaware and do not understand the condition – and where treatments are very costly. I have to travel to the US to purchase minoxidil products suggested by my physician... Frustrating to say the least...

Private and/or public funding

It is not surprising that funding was the most anticipated challenge expressed by the majority of participants. Several participants indicated that they felt such an organization would require government funding during the inception stage. The sentiment of responses referring to issues of funding seemed to be somewhat negative. Many participants expressed frustration at their inability to secure adequate insurance coverage for hair pieces in Canada. Participants seem to feel that their needs and concerns as individuals with alopecia areata are not taken seriously by insurance providers or the government. Participants appeared quite unsure of where or how funding for an organization would be discovered:

> The startup time and energy would be massive plus the effort to find and secure funding
>
> Finding everyone with alopecia might be difficult. Advertising a new association could be expensive so there could be high start up cost but they did it in the USA so it's not impossible.
>
> Receiving funding initially – connecting people from across the country, reaching people in rural areas, getting the dermatologists on our side in terms of distributing information.
>
> Canadians are apathetic and selfish so funding will be a problem.
>
> Proving to government that there is a definite need for an organization in Canada.
>
> I've seen our government slowly destroy our health care system. I'm afraid they will put this on the backburner like other non-life-threatening diseases.

Misunderstanding of alopecia areata/ lack of public awareness

It is apparent that participants feel it would be difficult to find public support for a Canadian alopecia areata association. Participants seem to feel that finding both public understanding and validation of their struggles would be a substantial challenge. An organization for Canadians with alopecia areata would have to contend with the lack of awareness of this condition as well as with the fact that alopecia areata is not a life-threatening illness. Participants appear to fear public misunderstanding of alopecia areata as simply a "cosmetic" disorder and, therefore, not a legitimate health concern:

> On account of the fact that Alopecia isn't life threatening I think it would be hard to establish and express to people that it really is a horrible disease mentally and emotionally.
>
> The ignorance of the population towards this condition which is sometimes unknown – or seen as a purely esthetic condition.
>
> Some people may not consider this association a necessary thing. Many think because you don't die from this disease that it isn't terrible. I disagree – because the psychological impact is

> devastating especially as a child and teenager. I almost committed suicide as a teenager because I was so insecure. I wish I would have had contact with someone who understood what I was going through to help me through it.
>
> The just live with it attitude I've encountered.

Lack of commitment from the medical community

Participants seemed to agree that a partnership with the Canadian health professionals would be necessary for the success of a national association for Canadians with alopecia areata in both initiation and maintenance of service. There seems to be concern that doctors and dermatologists are currently lacking knowledge and sensitivity to the emotional impact of alopecia areata and, therefore, it may be difficult to secure their expertise and endorsement:

> Doctors and dermatologists don't really know about the disease. They just don't know what to do. So you are alone in this situation until you hear that someone else got that a few years ago.
>
> Getting the dermatologists on our side in terms of distributing information.
>
> Promotion – would love to see doctors get more involved in referring patients to national association for information. Canadian apathy.
>
> I do not think it would be easy to access many of the Canadians afflicted with this condition because the doctors do not refer patients to NAAF. There would have to be ads across the nation informing people of the disease and where to seek help.

Volunteers (human resources)

The success of many organizations is due, in large part, to their network of committed volunteers. Participants expressed concern that it would be difficult to locate and retain motivated and dedicated volunteers to assist in the hard work required to organize and maintain a national association for Canadians with alopecia areata:

> It requires people to set it up and organize it and they may be hard to find.
>
> Finding and getting participants and members given the current non-existing network.
>
> You have to have a strong team of dedicated individuals to carry out such an assignment.
>
> Finding and keeping a leader.

Overall Themes

The cross-analysis of all open ended questions during *axial* or *second level* coding led to the development of three general categories which I labeled *Isolation*, *Being Bald and "Invisible"*, and *Breaking the Silence.* It was striking to see how participants made use of the space given to them to express their experiences, ideas, and opinions. Participants shared their vulnerabilities, their emotions, and pieces of their stories as Canadians contending with alopecia areata. For most, it seemed this was their first opportunity to express their needs and "have their say". The overall tone and theme conveyed by the qualitative data was the perception of this research as an exercise of "breaking the silence." Description and elaboration of this concept will occur at the end of this section.

Isolation

The theme of isolation was strewn throughout most of the responses to questions. Canadians with alopecia areata are spread all over this great country and many shared their struggles in getting a diagnosis, finding treatment, accessing head coverings, getting information, and finding support. It was common for a participant to state that they felt alone with this disorder. Many felt that they could not share their disorder with others which appeared to contribute to their feelings of distress and isolation:

> I was shocked that Canada does not support AA. It made me feel very alone – like I had some very rare disease and could not get information on it.
>
> Alopecia is not like other diseases – it is unique – it is devastating – it is personal – it is non-life threatening. It threatens your soul – not your life.
>
> I was the only person on earth who had this disease as far as I knew.

Being Bald and "Invisible"

As I reviewed the responses of Canadians with alopecia areata, the concept of "invisible" continuously came to mind. The 1997 Merriam-Webster Pocket Dictionary defines invisible as: (1) "incapable of being seen" and (2) "hidden." There were several references by participants to individuals with alopecia areata being "in hiding." Whether keep their condition personal by wearing a wig or avoiding conversation about it, many participants did not feel safe in sharing their experiences with others. The lack of public awareness and access to credible information on alopecia areata likely contributes to the practice of keeping this disorder "hidden." Hiding this medical condition, however, may cause the denial or minimization of the experience of having the disorder, positive or negative. As a result, Canadians with alopecia areata appear to perceive their feelings, experiences, and challenges as "invisible" or, in some cases, unworthy:

> Getting people to admit they have the problem in public. Good luck with that. I've been dealing with this for 20 years and I've only told 2 people outside of my family. It's so humiliating.
>
> The few people I have spoken to about alopecia have concurred that it is extremely embarrassing. Most people do not want to talk

> about it. It's also misunderstood because it seems vain to be so disturbed with hair loss.

It was very common for me to come across an entry of a participant describing their experiences of receiving a diagnosis of alopecia areata and then being sent on their way with no information and no support. There was an overwhelming expression of the pain and suffering of hair loss by Canadians coupled with the experience that these feelings were "incapable of being seen" by members of the medical or public community. When their feelings were not validated, individuals with alopecia areata tend to display signs of guilt for the devastation and trauma they experienced from a seemingly "cosmetic" or non-life-threatening disorder. It is evident that they are left to cope with their psychological and/or emotional distress and the public misperception of their baldness alone:

> There is an emotional exponent with this condition as much as there is a physical one. People without it don't understand how emotionally painful this condition is. It is one thing to be a bald man – but a bald woman without cancer going thru chemo is another. Hair loss on a woman is unattractive. And the media perpetuates this fact everyday in the cover of magazines – television and the like.
>
> Alopecia areata is not life threatening but it is certainly life altering. It is extremely hard to accept and it threatens every aspect of my life. A bald man can appear bold and confident – but a bald woman looks like she has cancer.
>
> This is such a judgmental disease – people are very rude and for a child this is so hurtful. What a wonderful life this would be if people could just accept others as they are. My son is a beautiful child and kind – but he is judged by his appearance.
>
> I think the mental health component of this disorder is paramount especially where children are concerned. My son lost his hair when he was 6 years old. He will be 10 years old in July and has recently been diagnosed with depression and generalized anxiety

> disorder and is on antidepressants. I fear for his development into adolescence. I really feel strongly that there needs to be more emphasis placed on the emotional needs of these children as they navigate the challenges of growing up looking very different in a society that values physical appearance over almost everything else.
>
> Why didn't I receive this 23 years ago. The emotional trauma is very difficult. Being afraid to get close to anybody for fear of rejection. The mind set in ways provides positive reinforcement for the condition. Just the emotional state I feel perpetuates the condition.

Breaking the silence

It was very clear that this sample of Canadians with alopecia areata welcomed the opportunity to express their needs as a community. Participants used this forum to share their experiences with alopecia areata and their vision of specialized service to them in Canada. I was overwhelmed by what I read. It felt as though their voice had been silenced in the past. Given a space where their voice was valued, this "invisible" community was eager to "break the silence" and be heard. Many responses referred to frustration with and disappointment in the services available to them in Canada. This sample of the population agreed that local services were inadequate and they seemed to feel strongly in favour of the creation of a national organization for Canadians with alopecia areata:

> I am very happy to see that someone has recognized the possibility that there is a need for this organization. The NAAF simply cannot provide the kind of support to Canadians that we need. Canadians have their own health care and issues. We need a means to find answers to this disease. The two organizations could trade information to help find a cure if a Canadian organization was created. The greater the amount of data researched – the better.

I am pretty confident that people with alopecia will be enthusiastic about setting up a national organization. I know I would be willing to devote a lot of time and money to such a group. Mainly to give young children the mental support and confidence they may lack.

Chapter 6 – Discussion and Conclusions

Summary of Results

Quantitative and qualitative analysis revealed a tremendous majority (83.1%) of this sample (134) strongly feel there is a need for a national organization serving Canadians with alopecia areata. An additional 10% agree a national organization is necessary. This opinion was echoed in the qualitative data. Almost three quarters of the participants (73.9% - 99) were women with more than half (58.2% - 57) indicating an age between 20 and 39 years. Most participants (83.6% - 112) stated that they had alopecia areata and 48.2% (54) reported complete loss of scalp hair at some point in their life. Ontario was the province with the most representation, comprising 50.4% (67) of the sample.

Crosstabulations and chi-square analysis was employed to determine if there were differences in perception of need for a national organization in Canada according to province of residence, age, gender, type of alopecia areata, and whether family member or person with alopecia. No statistically significant relationship was discovered between any of the above variables and perception of need. Provision of support was identified as the most essential (80.3% - 102) objective of a national organization for Canadians with alopecia areata, and 87.6% (103) participants indicated that they would be willing to pay an annual membership fee to such an organization.

The concepts of isolation, being bald and "invisible," and breaking the silence emerged from the qualitative analysis. It was clear that Canadians with alopecia areata experience both emotional and physical isolation as they struggle to find the most basic of services. The hidden nature of this disorder appears to contribute to a sense of loneliness and, in many cases, a decline in feelings of worth. Many participants shared instances or fears that their experiences with hair loss were either misunderstood or devalued by others. Participants exercised their voice and broke the silence by sharing their experiences, thoughts, ideas, and hopes for an alopecia areata association in Canada.

The idea of "voice" has been central to this project. I conceptualized this research study as a needs assessment and, as such, a forum for the voices of Canadians with alopecia areata. My quest to expose the voices of Canadians with alopecia areata proved to be meaningful on multiple dimensions. The result was a compelling collection of data confirming that Canadians - young and old, male and female, and from all corners of the country - agree there is a real and present need for the creation of a Canadian alopecia areata association. As a researcher, I had the opportunity to "connect the dots" and relate a tremendous story of pain, courage, strength, and need. As a woman with alopecia areata, I was able to recognize their story as my own and appreciate my fortunate position to assist this population in "breaking the silence." This sample of Canadians with alopecia areata proficiently conceptualized their needs and shared a remarkably clear vision of an organization to serve their community.

Reflections on the Research Process and Findings

Vulnerability in Research

I attended my first NAAF patient conference in St. Louis the summer prior to my entry into graduate studies. This experience was life-altering for me as I realized the value of meeting others with alopecia areata. It was following this experience that the idea for this project began to take form in my mind. I entered into it with conflicting emotions. While I was exuberant to have the opportunity to conduct research on

Canadians with alopecia areata, I was also keenly aware that this project involved a high degree of personal vulnerability.

My undergraduate training ingrained a positivist expectation of myself as objective expert. It was, therefore, extremely challenging for me to locate myself in this research. As a social work student with a science background, I found it difficult to negotiate between professionalism and self-revelation. Indeed, this task seemed debilitating at times as the project signified my formal entry into research and, in particular, to feminist methodology. I was unsure of how to conduct myself in my new role as researcher and emerging feminist. This uncertainty was intensified by my very personal connection to the research topic. There were several points in the research process that I questioned my ability to complete my thesis as I found the introspection required of me to be overwhelming. Writing vulnerably involves personal risk, requires dedication and intensive support from others, and demands an honesty with oneself that is not easily achieved.

Despite these demands, reflexive ethnography (Behar, 1996; Ellis & Bochner, 2000) allowed me to become a participant in this thesis and truly recognize the value of what I set out to do. To find a purpose in this world is to feel alive, to recognize personal strengths and exercise them in a way previously unimagined, to approach challenges with hope and dedication, and to have the courage to follow dreams. My thesis work has clarified my purpose and empowered me to pursue my passion to serve the Canadian community of individuals coping with alopecia areata in a capacity I could not have anticipated at the beginning of this process. The outcome was a piece of work that was undoubtedly meaningful for myself and I believe it was meaningful for my participants as well. I only hope it will have meaning for the reader.

Gender and Alopecia Areata

In the development phase of this study, I constructed the survey tool to be inclusive of adult Canadians of both sexes with alopecia areata and to parents of children with alopecia areata. Upon completion of my research proposal, however, it became clear to me that I had conceptualized this study through a gendered lens. While my survey remained open to both men and women, I had chosen to focus on the experience of women with hair loss, as I assumed this topic to be of greater concern to women. Indeed, several studies indicated that both girls and women seem to have more anxiety, lower self-esteem, less sense of control over their lives, negative body-image feelings, and more depressive reactions to their hair loss (Cash, 1999; Cash, Price & Savin, 1993; Girman et al., 1999; Liakopoulou et al., 1997; van Der Donk et al., 1994). These results made sense considering our long cultural history of attaching the concepts of femininity, attractiveness and sexuality in women to their hair (Cooper, 1971; Levine, 1995; Firth, 1973). Given my personal experience and the reviewed literature on the meanings of hair and hair loss, I made a wide-sweeping assumption that the large majority of my participants would be female and so I felt both comfortable and confident in adherence to and employment of feminist theories and practices.

I was surprised, therefore, to discover that one quarter (26.3%) of my sample was, in fact, male. This is a much higher male response rate than I had anticipated. Indeed, it was extremely interesting to note that the responses of men and women with alopecia areata were quite similar in nature. Further, males under the age of 20 years constituted the majority (28.6% - 10) of this male sample. These results suggest that there may be value in adopting a gender perspective in understanding the experiences of Canadians with alopecia areata, rather than a purely feminist perspective. My impressions/reactions to this result are discussed in greater detail under the heading, implications for future research, presented later in this chapter.

Age of People to be Served by a Canadian Alopecia Association

Almost three quarters (67.9%) of participants indicated that they developed alopecia areata prior to the age of 19 years. The result (67.9%) in this study is slightly higher, yet still consistent with the findings of Liakopoulou et al. (1997) and Thompson and Shapiro (1996) where 60% of reported cases of alopecia areata developed in individuals under the age of 20 years. These numbers suggest that a Canadian alopecia areata association should offer and direct age-appropriate services, support and otherwise, to children and youth. Indeed, 85% of respondents under the age of 20 years indicated that they strongly feel a need for the creation of a national association. Given that research has documented a high incidence of psychopathology in children with alopecia areata (Colon et al., 1991; Liakopoulou et al., 1997; Reeve, Savage, & Berstein, 1996), I believe it would be important for any organization serving Canadians with alopecia areata to include services to children and youth in the mandate of the organization, and to consult children about which services best meet their needs.

External/Public Themes

It was very clear that this sample of Canadians with alopecia areata feel domestic service, medical and otherwise, is inadequate. Participants shared many disillusioning experiences with the medical community in securing an accurate diagnosis, locating information on the disorder and its treatment, and accessing any type of support services. Locating and accessing the most basic of services appears to be a struggle for Canadians with alopecia areata as it seems there really is just nothing out there for them in Canada. I have a difficult time understanding why the medical community and, in particular dermatologists, do not seem keep up to date with the research on alopecia areata. My own experience with this community echoes that of my participants in that the general response from the medical community is typically quite detached and feels rather uncaring. I am more knowledgeable about the latest research and treatment options than my dermatologists. I think it may be possible that the medical community has given up hope on treatments for alopecia areata as most have proved largely unsuccessful in the past. There is little known about the mechanisms of this disorder but there is substantial research being conducted in this area (NAAF, 2004). I think it might be necessary to send out research on alopecia areata to medical professionals as it is either not accessible to them or they are not making an effort to locate this research. It is possible that physicians are ill-informed and ill-equipped to deal with alopecia areata because it is medically benign and thus, not a pressing concern to this community.

This group of Canadians with alopecia areata appeared sensitive to the perceptions of others regarding their hair loss. They indicated that a lack of public awareness of this condition contributes to the perpetual misunderstanding of their baldness. In particular, these participants seemed to believe that both the public and medical professionals lack compassion and understanding of the emotional trauma of hair loss. Such ideas contribute to an acute sense of shame for the feelings of devastation experienced by individuals with alopecia areata.

Internal/Private Themes

Perhaps the most revealing and/or striking outcome of the qualitative data was the feelings/experiences of isolation described by Canadians with alopecia areata from both rural and urban regions. Given the geography of this country, overcoming isolating effects may be one of the greatest challenges of a national organization.

In my experience, many individuals with alopecia areata are able to cope with being bald; it is those around us who seem incapable of doing the same. Wearing a wig allows me anonymity that baldness does not. The moment I remove my wig and step into a public space, it is apparent that I am seen to be on display and vulnerable to the stares, ideals, and assumptions of others. It is moments like these that I would want to become "invisible" and, in essence, I can if I wear my wig. This theme of "being invisible" was very present and difficult to conceptualize in my qualitative analysis. It would appear that many individuals with alopecia areata seek invisibility by covering their very visible condition of baldness. The quest for invisibility is, therefore, self-protective. In the achievement of invisibility, however, the experience, emotions, challenges etc. of being bald are not seen and thus, not acknowledged by others. The quest for invisibility is, therefore, also undermining. Living with alopecia areata is very difficult to negotiate as we crave support and recognition yet we do not want to be "seen."

Barriers in Accessing Services

Another interesting finding was the absence of representation from Northern Canada. There were no participants from any of the three northern territories (Yukon, Northwest Territories, and Nunavut). An entire segment of the Canadian population is therefore, not represented in this data. Upon reflection, I entertained several possible explanations for this absence. My initial thought was that geography may isolate individuals with alopecia areata. It is quite possible that there is limited access to resources for alopecia areata in the North. Participants from other provinces indicated difficulties in securing an accurate diagnosis and in finding treatment options, therefore, it is likely that the same is true for Canadians with alopecia areata in Northern Canada. Culture may also play a role as there may be less pressure to adhere to dominant cultural definitions of beauty. There may have been a language barrier that prevented some Northern Canadians from responding to the online survey. There may also have been financial barriers to participation. As noted in the results, many participants were members of NAAF and thus probably heard about this study through the e-mail invitation forwarded to Canadian members of NAAF. An annual membership to NAAF costs 35 American dollars and may be a deterrent to connecting with this resource. Finally, it may be that many other communities of a similar size population (just over 100,000) are also without participants in this study. Clearly, a national organization for Canadians with alopecia areata would need to find creative methods to overcome geographical, language, and financial barriers to service.

Building a Canadian Alopecia Areata Association

Canadians coping in some way with alopecia areata shared a remarkably uniform vision of how a Canadian alopecia areata association might look. The establishment of a new program requires the precise specification of objectives (Cox et al., 1979). I drew upon the program logic model as method to outline the objectives of a prospective

Canadian Alopecia Areata Association. This model visually represents the relationship between: 1) the activities provided, 2) the service delivery, 3) the intermediate results, and 4) the ultimate results (Wong-Rieger & David, n.d.). In developing a new program, mapping out program activities and linking them to intermediate and ultimate results provides a direct way to measure goal achievement and, therefore, may be later used as a resource for efficient program evaluation (See Figure 1, Appendix F)

Mission Statement

The mission of the Canadian Alopecia Areata Association might be: "To enhance the quality of life of Canadians with alopecia areata through provision of local support services, promotion of public and professional awareness, support of socio-emotional and medical research, and advocacy of the needs of individuals and families coping with alopecia areata."

Together, Canadians with alopecia areata will attain their goals to connect with others, access support, and build understanding and acceptance of alopecia areata. The objectives of a Canadian Alopecia Areata Association, as identified by this research sample, are presented below according to level of importance with objective number one being the most important:

Organizational Objectives

1. Provide support to individuals with alopecia areata in Canada
2. Supply information/education materials for individuals with alopecia areata and family members
3. Advocate for improved health care and insurance policies as they pertain to hair loss/alopecia areata

4. Fund medical research on alopecia areata
5. Provide current resource materials/ research on the status of the condition, its treatment, and the psychological impact of a diagnosis of alopecia areata to family physicians and dermatologists
6. Network individuals with alopecia areata in Canada
7. Promote public awareness of the condition
8. Fund socioemotional and psychological research on alopecia areata
9. Provide support to family members of individuals with alopecia areata
10. Provision of educational resources to professionals who may serve individuals with alopecia areata (i.e. hair care professionals, social workers, psychologists)

A substantial portion of NAAF's income is directed to the funding of research that "adds to the scientific knowledge about alopecia areata, its causes, and different treatments", which is a major component of their mission statement (NAAF, 2004). The intent and objectives of a Canadian organization for individuals with alopecia areata would require clarity in relation to our American counterparts. One possibility is that the Canadian association would not have research as part of its mandate; another is that it would fund research with a focus on socioemotional and psychological issues, but not medical ones. In this way, the activities of the two organizations could be complementary rather than competitive. NAAF has acquired deserved respect, admiration, and prestige as the first and only resource for individuals with alopecia areata in North America. The efforts of its founder, Dr. Vera Price, in research and support for people with alopecia areata is indeed phenomenal and should not be minimized by the establishment of an organization in Canada.

Building Alliances

The success of the establishment of a national organization and the program activities outlined in Figure 1 (Appendix F) will require the development of alliances or collaborative relationships. Community provision of services in the current environment is often achieved through inter-agency partnerships "based around a shared interest and involvement with a particular client group" (Trevillion, 1992). These inter-agency links may be difficult to create, as agencies and programs often find themselves in competition with each other for required resources (Cox et al., 1979; Trevillion, 1992).

A promising possibility, however, would be for a Canadian Alopecia Areata Association to form a coalition with NAAF. Such a relationship would include working together on mutual goal attainment (Cox et al., 1979). In reality, the establishment of a Canadian organization could serve as an extension of service to Canadian citizens with alopecia areata but it is clear from the findings of this study that long-term goals would essentially parallel those of NAAF. These goals include improved public awareness of the condition, facilitation of support services for individuals with alopecia areata, empowerment of alopecians, advocacy to government, and, ultimately, support of research efforts to improve the quality of life for individuals with alopecia areata and, eventually, to discover the cause of and cure for alopecia areata. The development of this shared understanding and an open and effective communication network between organizations will assist inter-agency partnership (Trevillion, 1992).

Funding

For the past two decades, NAAF has assumed leadership over the North American community of individuals with alopecia areata as the sole support and information resource for this community. NAAF acquires financial support from Canadians through their membership and conference fees and various donations from the fundraising efforts of Canadian support groups. It may be possible to negotiate funneling these resources, or a portion of them, to a Canadian association. Other funding avenues to be explored might be the presence of a prominent family with a member coping with alopecia areata, any possible celebrity figures with a tie to alopecia areata, and organizations/foundations interested in children and body image and/or mental health.

Overcoming Feelings of Disempowerment

It was apparent that Canadians with alopecia areata feel as though their needs will be both misunderstood and minimized or ignored by the general public and government due to the perceived "cosmetic" nature of this disorder. Alopecia areata is a medically benign condition (Thompson & Shapiro, 1996). This is a legitimate concern in securing both societal support and funding for a national organization. As a society, we want to improve the human condition and the first step towards such a goal is determining the cause and cure for life-threatening disorders and diseases. Hair loss is not a physical disability and it is easy to assume that it would have a minimal impact on a person's ability to lead a "normal" life or even interfere with quality of life. Many participants described situations in which friends, family and medical professionals perceived their hair loss as cosmetic and encouraged them to simply get over the "inconvenience" and purchase a wig.

I think that Canadians with alopecia areata require their needs to be validated by the medical community or some other profession perceived as "powerful" in order for them to truly believe themselves to be deserving of specialized national service. A tone of *cautious* optimism was present amongst this sample and these feelings require timely reinforcement. It will be difficult to secure support for an organization if Canadians with alopecia areata do not rally behind the cause. I am concerned that Canadians with alopecia areata will experience both disappointment and negative reinforcement if this study is not followed up by further action in the next few years.

Outreach

It has proven to be very difficult to locate Canadians with alopecia areata. It has been brought to my attention, by a well-respected dermatologist in Canada, that the creation of a Canadian Alopecia Areata Association can simply not be justified by the population base that exists in Canada. In comparison to the United States, the population of Canadians with alopecia areata is significantly smaller (approx 310,000 vs 4.5 million in the U.S.). The fact remains, however, that the same *proportion* of our population have the disorder in Canada and the United States; the smaller numbers in Canada reflect the difference in overall population between the two countries. I am not sure how much weight to assign this numbers argument. The same proportion (1%) of the Canadian population have the disorder epilepsy, a medical condition which has organizational representation in Canadian society. A national organization would not only serve the 1% of individuals diagnosed with alopecia areata, but their family members as well. This would translate into a service population of at least 3% of Canadians, with an average family size of 3.0 (Statistics Canada, 2004). It is important to recognize that professionals such as physicians, social workers, psychologists, teachers, and those involved in hair care may all be potential members of the association as well. I believe the only way to truly assess the size of the service population is through actual provision of service and program evaluation.

Implications for Future Research

A review of the literature on alopecia areata revealed a definite lack of research on the socioemotional experience of this disorder and the needs of individuals with alopecia areata. The results of this study indicate that individuals with alopecia areata feel alone and misunderstood in coping with hair loss. It was apparent that participants felt valued and perhaps even validated, by the simple knowledge that research was being conducted on their experiences and needs as individuals with alopecia areata. Qualitative analysis uncovered a community with a strong voice and a compelling story. I firmly believe that this study only touches upon the experiences of Canadians with alopecia areata and further research, especially qualitative study, would contribute to multiple disciplines, both in study and in practice.

Future studies on alopecia areata should address the concept of race as this was a limitation of the current study. As the second most visible physical sign of race (Cooper, 1971), hair may have different meanings both within and between different races and/or cultures. Race was not addressed in the current study and, I believe the variation in meanings of hair and hair loss merits future investigation.

The findings of this study indicate that issues of body image, isolation, and misunderstanding are of great importance to the male sample of Canadians with alopecia areata. This finding raised several questions for me: Are young men vulnerable to societal pressures to occupy a certain image? Are young men judged or valued according to their outward appearance or level of physical attractiveness? What are the meanings of hair to young men? Do the media endorse ideal physical standards for young men? Such questions may appear to be in tension with both my feminist values and the body image literature reviewed in this study. While addressing these questions may evoke some criticism from the feminist community, I truly feel that they are worthy of investigation. We live in a culture that preys upon the insecurities of youth and bombards this population with media suggesting that a certain outward appearance is the key to happiness and success. This data would suggest value in the study of the construction of self-image and self-esteem of young males.

Implications for Social Work Practice

Given the result that alopecia areata affects (and appears to reduce) the quality of life of this group of Canadians with alopecia areata, there are real and present implications for social work practice. It is very possible that Canadians with alopecia areata are or will access formal support services provided by social workers, therefore, I believe these professionals require both medical and psychosocial education about alopecia areata. As social workers work with individuals, groups, and families, I believe it would be necessary for them to understand socio-emotional and psychological issues that challenge people with alopecia areata and their family members. As a disorder common in childhood, alopecia areata is a family condition, affecting each member in different capacities. Professionals need to understand that hair loss affects children, youth and adults and that issues related to alopecia areata will change with age and development. It appears, from this research, that gender differences may not be very great between among young males and females. Coping with alopecia areata does not seem to be simple for either sex at any age.

Conclusion

My current academic goals have stemmed from my personal experience with an auto-immune disorder called alopecia areata. This disorder causes unpredictable hair loss in men, women and children and is present in approximately 1% of the Canadian population. Current services for Canadians with alopecia areata are limited to interactions with family physicians, dermatologists, support affiliates with the National Alopecia Areata Foundation in the United States, and international internet resources.

The general research objective of this study was to determine (through a web-based survey) if Canadians with alopecia areata and their families perceive the need for the creation of an organization providing support and services to them in Canada. A total of 134 Canadians completed a self-administered web-based questionnaire that yielded both quantitative and qualitative data. The results indicated that 93.8% of respondents feel there is a strong need for the creation of a Canadian alopecia areata association. The concepts of isolation, being bald and "invisible," and breaking the silence emerged from the qualitative analysis

The results of this study are very clear. Canadians with alopecia areata feel strongly that there is a need for a national organization to meet their unique needs. I believe momentum for such an endeavor could be gathered and maintained in the coming years. I believe a large media campaign and partnership with the Canadian medical community, in particular the Canadian Dermatology Association, may be necessary to secure the support necessary to start such a project. As an independent nation, a national body of representatives is required to advocate for our collective interests and meet our unique needs as Canadians with alopecia areata.

Appendix A

Participant information letter/consent form

WILFRID LAURIER UNIVERSITY

Faculty of Social Work

Information Letter

The Bald Truth: Determining the need for a Canadian Alopecia Areata Association

Investigator: Bonnie Lipton – Master of Social Work Student at WLU

You are invited to participate in a research study aimed at exploring if a need for increased service exists among Canadians with alopecia areata and their family members. The purpose of this study is to establish if there is support for the creation of a national self-help organization for individuals with alopecia areata in Canada.

Specific research objectives of this study include: to survey Canadians with alopecia areata and their family members to determine if they perceive a need for a national organization and what services, if any, they require; to determine what Canadians with alopecia areata perceive the objectives of a national organization should be and what role they would like to see such an organization take; to determine how Canadians with alopecia areata would like to see services of a national organization be delivered; and to determine how services might be funded.

The survey will take approximately 10 -15 minutes to complete. Data will be examined to determine if there is a felt need for the creation of a national self-help organization for Canadians with alopecia areata. Results of this study will be reported in a thesis and summarized in a research report which will be posted on the website created for this project. The National Alopecia Areata Foundation and Alopecia Areata support group leaders in Canada will each receive a copy of the results of this study. The results of this study may appear in academic publications and/or presentations. All identifying information will be removed from any quotations that appear in the thesis, research report, publications, and/or presentations.

Your participation in this survey is voluntary. You have the right to decline participation and you have the right to refuse to answer any questions at any point in this survey. Survey participation may be discontinued at any time by exiting the survey in your web browser.

Confidentiality will be respected in this research process. You are not required to place any identifying information on completed surveys. Survey data will transfer directly into a secure, password protected server address and would be impossible to trace once submitted. Confidentiality of information cannot be ensured while data is in transit in the internet. All data will enter a composite statistical file stored on the hard drive of the personal computer of the principal investigator and will be deleted following the completion of the thesis and summary report. Data will only be accessible to the primary investigator (Bonnie Lipton), thesis supervisor (Anne Westhues, professor, Faculty of Social Work, Wilfrid Laurier University), and research assistants who will assist with data entry and data management. All received information and data will be kept confidential by the above parties.

Following completion of the survey, you will have the opportunity to provide your contact information if you wish to be included in a list of Canadians interested in establishing a national organization for alopecia areata. Contact information forms will be entered into a separate database and, therefore will be reviewed independent of returned questionnaires. Your name and any other identifying information will not be associated with questionnaire responses.

Your participation in this survey is valued and will be extremely important in identifying whether there is a need for a national organization for Canadians with alopecia areata and their family members. Your participation will allow you to express your service needs as an individual with alopecia areata or a family member of someone with alopecia areata. It is important to note that this research is exploratory and may not result in direct action in the Canadian community of alopecia areata.

This project has been reviewed and approved by the Research Ethics Board at Wilfrid Laurier University, Waterloo, Ontario, Canada. If you have questions at any time about this research study or questionnaire, please feel free to contact the investigator, Bonnie Lipton at lipt1482@wlu.ca. If you have any questions regarding your rights as a participant or feel that they have been violated, please contact the Dr. Bill Marr, Chair, University Research Ethics Board at WLU, (519)884-0710, extension 2468.

Thank-you for your time and input, it is much appreciated.

Sincerely,

Bonnie Lipton
M.S.W. Student, Faculty of Social Work
75 University Avenue West, Aird Building, 4th Floor,
Waterloo, Ontario, N2L 3C5, CANADA
E-mail lipt1482@wlu.ca

I have read and understand the above information. I can print off a copy of this form for my own records. By clicking "I agree" you consent to participation in this study.

Appendix B

Questionnaire

THE BALD TRUTH:
Determining the need for a Canadian Alopecia Areata Association

This questionnaire was designed to determine if there is a need for increased service in the form of a national organization for Canadians with alopecia areata and their family members.

I have read the description of the study, and I have decided to participate in the research project described here. I understand that I may refuse to answer any (or all) of the questions at this or any other time.

Please answer each item by placing a check mark in the response(s) box (☐) that most accurately describes your experience.

1. Sex: ☐ Male ☐ Female
2. Age: ☐ under 20 years ☐ 20 - 29 years ☐ 30 – 39 years ☐ 40 – 49 years ☐ 50 + years
3. Province of current residence: ☐ British Columbia ☐ Alberta ☐ Saskatchewan ☐ Manitoba ☐ Ontario ☐ Quebec ☐ New Brunswick ☐ Nova Scotia ☐ P.E.I. ☐ NFLD ☐ Territories
4. AT ANY TIME IN YOUR LIFE HAVE YOU HAD ALOPECIA AREATA, TOTALIS, OR UNIVERSALIS?

   ☐No → go to question 10 ☐ Yes - (continue)
5. Age of first onset of AA/AT/AU: ___________
6. The greatest amount of hair loss ever experienced on your scalp is

   ☐ None ☐ Up to 25% ☐ 26-50% ☐ 51-75% ☐ 76-99% ☐ 100% (completely bald)
7. Have you lost body hair? ☐ No or ☐ Yes→ ☐ Some hair, ☐ All hair
8. Are nails involved? ☐ No or ☐ Yes → ☐ Some nails ☐ All nails
9. How many episodes of AA/AT/AU have you had?

   ☐ Only 1(Including Continuous) ☐ 2-5 ☐ 6-10 ☐ > 10 ☐ Too many to count ☐ Don't know
10. At the time of you/ your child's diagnosis of Alopecia Areata, where did you receive information on support services beyond medical care?

    ☐ Family physician
    ☐ Dermatologist
    ☐ National Alopecia Areata Foundation (NAAF)

☐ Internet (please specify) ____________________
☐ Other (please specify) ______________________

11. Are you currently accessing support services?

☐ Yes ☐ No

11 (a) If yes, please indicate the service provider

☐ National Alopecia Areata Foundation
☐ Local support group for AA
☐ Internet
☐ Phone support line for AA
☐ Mental health professional (psychiatrist, psychologist, social worker etc.)
☐ Health professional (family physician, dermatologist)
☐ Other (please specify) _________________________

12. Do you feel that you have adequate access to information and support for Alopecia Areata by providers in Canada?

1 completely inadequate	**2**	**3**	**4**	**5** completely adequate

12. (a) Please comment on the strengths of Canadian services in the space provided.

____
____
____
____

12. (b) What, if any, of your needs as a Canadian with alopecia areata or a family member of an individual with alopecia areata were not met through accessing services available in Canada. Please respond in the space provided.

____
____
____
____

13. Are you familiar with the National Alopecia Areata Foundation (NAAF)?

☐ Yes ☐ No

13. (a) If yes to the above, are you a member of NAAF?

☐ Yes ☐ No

13.(b) Have you used any services offered by NAAF? If yes, please indicate the service in the space provided.

☐ Yes ☐ No

____
____
____

13. (c) If yes to the above, please comment on the strengths of these services in the space provided.

____
____
____
____

13.(d) What, if any, of your needs as a Canadian with alopecia areata or a family member of an individual with alopecia areata were not met through accessing services through NAAF? Please respond in the space provided.

____
____
____
____

14. Do you feel there is a need for a national alopecia areata association in Canada?

1	2	3	4	5
strongly disagree there is a need				strongly agree there is a need

14(a) If you feel there is a need, what should be objectives of such an organization? Place a ***1*** next to all objectives you see as ***essential;*** a ***2*** next all those you see as ***very important***; and a ***3*** next to all those that ***may not be necessary.***

☐ network individuals with alopecia areata in Canada
☐ provide support to individuals with alopecia areata
☐ provide support for family members of individuals with alopecia areata
☐ supply information/education materials for individuals with alopecia areata and family members
☐ promote public awareness of the condition
☐ advocate for improved health care and insurance policies as they pertain to hair loss/alopecia areata
☐ fund medical research on alopecia areata
☐ fund socioemotional and psychological research on alopecia areata
☐ provide current resource materials/research on the status of the condition, its treatment, and the psychological impact of a diagnosis of alopecia areata
☐ Other ***please specify***:
____
____

15. How would you like services of a national organization for alopecia areata in Canada to be delivered? ***You may select more than one response.***

☐ Phone information and support line
☐ Brochures/Pamphlets
☐ Internet chat rooms/message boards
☐ Organized support groups
☐ Annual conference for individuals with alopecia areata and their family members
☐ Annual camp for children with alopecia areata
☐ Newsletters
☐ All of the above

16. Would you be willing to pay a membership fee each year to an organization for individuals with alopecia areata and their family members?

☐ Yes ☐ No

16.(a) If yes to the above, what rate would you consider reasonable for a one year membership per adult?

☐ $10.00 ☐ $15.00 ☐ $20.00 ☐ $25.00 ☐ $30.00
☐ $40.00 ☐ greater than $40.00

16.(b) Should there be a child or family membership rate in addition to the individual membership fee?

☐ Yes ☐ No

17. What are the challenges you anticipate in setting up a national association serving Canadians with alopecia areata? Please respond in the space provided.

____
____
____
____
____
____

18. Please take the space provided to express any additional comments, thoughts, needs etc. that are not addressed in the current questionnaire and which you deem to be relevant to this study

____
____
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____
____
____

Thank-you for participating in the questionnaire for this study.
You may contact us with questions/concerns any time at:
The Bald Truth: Determining the need for a Canadian Alopecia Areata Association
c/o Bonnie Lipton
Faculty of Social Work
75 University Avenue West, Aird Building, 4th Floor,
Waterloo, Ontario, N2L 3C5, CANADA
PHONE (519) 884-0710
FAX (519) 888-9732
E-MAIL lipt1482@wlu.ca

Appendix C

Contact Information Form

YES ! I am interested in being a part of the creation of a National Canadian Association for Alopecia Areata !

The following information will be kept confidential at all times and will not be associated with questionnaire results

I consent to have this information added to a national mailing list of Canadians interested in the possible formation of a national organization of support and representation in Canada.

Please fill in all the blanks or check the appropriate boxes, the starred fields (*) are optional:

Last Name: ______________________ Date: MM / DD / YYYY

First Name: ______________________Middle__________

Primary Contact Address: ______________________________________

____

Secondary Contact Address: ____________________________________

____

Telephone Number: (Home)__________________(Work)__________________

*FAX: _______________*Email: _______________

1. Do you have a diagnosis of alopecia areata? ☐ No ☐ Yes
2. Does your son/daughter have a diagnosis of alopecia areata? ☐ No ☐ Yes
3. Are you interested in assisting in some way to the creation of a national organization for individuals with alopecia areata in Canada? ☐ No ☐ Yes
4. Are you interested in accessing services/resources from an organization for Canadians with alopecia areata? ☐ No ☐ Yes
5. Would you like to receive feedback on the results of this study? ☐ No ☐ Yes
6. Can we contact you by: ☐ Phone ☐ Mail ☐ E-mail ☐ Fax

Thank-you for your interest and participation
You may contact us with questions/concerns any time at:
The Bald Truth: Determining the need for a Canadian Alopecia Areata Association
c/o Bonnie Lipton
Faculty of Social Work
75 University Avenue West, Aird Building, 4th Floor,
Waterloo, Ontario, N2L 3C5, CANADA
PHONE (519) 884-0710
FAX (519) 888-9732
E-MAIL lipt1482@wlu.ca

Appendix D

E-mail invitation

The Bald Truth: Determining the need for a Canadian Alopecia Areata Association

Are you a *Canadian* with *alopecia areata, totalis*, or *universalis* or a *parent/family member* of a *Canadian* with this condition? If so, I would like to invite you to participate in a research study.

I am conducting my Master's of Social Work thesis, under the supervision of Dr. Anne Westhues of the Faculty of Social Work, Wilfrid Laurier University, Waterloo, Ontario, Canada. The purpose of this project is to determine if Canadians feel there is a need for the creation of a national self-help organization for individuals with alopecia areata in Canada. Personal experience with alopecia totalis and universalis for the past 20 years has inspired and driven my current research objectives.

As a participant in this study, you will be asked to complete an online questionnaire which will take approximately 10-15 minutes. Confidentiality will be respected in this research process.

Any assistance you could offer in informing other Canadians with alopecia areata and their family members of my study by forwarding this e-mail would be greatly appreciated.

To participate, please click on the link below:

http://www.wlu.ca/fsw/thesis_bonnie_lipton/index.html

Thank-you!

Bonnie Lipton, B.Sc., MSW student
Faculty of Social Work
Wilfrid Laurier University, Waterloo, Ontario
E-mail: lipt1482@wlu.ca

Appendix E
Recruitment flyer

The Bald Truth: Determining the need for a Canadian Alopecia Areata Association

Are you a *Canadian* with *alopecia areata, totalis*, or *universalis* or a *parent/family member* of a *Canadian* with this condition? If so, I would like to invite you to participate in a research study.

I am conducting my Master's of Social Work thesis, under the supervision of Dr. Anne Westhues of the Faculty of Social Work, Wilfrid Laurier University, Waterloo, Ontario, Canada. The purpose of this project is to determine if Canadians feel there is a need for the creation of a national self-help organization for individuals with alopecia areata in Canada. Personal experience with alopecia totalis and universalis for the past 20 years has inspired and driven my current research objectives.

As a participant in this study, you will be asked to complete an online questionnaire which will take approximately 10-15 minutes. Confidentiality will be respected in this research process.

Any assistance you could offer in informing other Canadians with alopecia areata and their family members of my study would be greatly appreciated.

To participate, please access the following web site:

http://www.wlu.ca/fsw/thesis_bonnie_lipton/index.html

Thank-you!

Bonnie Lipton, B.Sc., MSW student
Faculty of Social Work
Wilfrid Laurier University, Waterloo, Ontario
E-mail: **lipt1482@wlu.ca**

Appendix F: Figure 1

Program Logic Model – Canadian Alopecia Areata Association

PROGRAM ACTIVITIES	SERVICE DELIVERY	INTERMEDIATE RESULTS	ULTIMATE RESULTS
Educational resources about alopecia areata for family physicians, dermatologists, social workers, psychologists, teachers, and hair care professionals.	Establish two brochures: 1) Outlining current research on the cause of the condition, new treatments, and success or limitations of older treatments 2) Presenting research on the socioemotional/psychological impact of hair loss in men, women and children. Including personal experiences as related by patients themselves.	• Increased awareness of the condition among general practitioners who are often the patient's first contact • Increased awareness of current research and practices in hair loss treatment • Increased recognition of the intense emotional consequences of losing hair in our society • Identification with a holistic view of the effects of hair loss	1) Improved client care and sensitivity to the emotional component of alopecia areata 2) Improved use and knowledge of treatment options 3) Delivery of more accurate and current information to clients with alopecia areata. 4) Improved understanding of the issues related to hair loss.
Support for patients and their families	1) Website with chat capability 2) Establish a support group in each province – run by local volunteers 3) Production of quarterly national newsletters 4) Annual support conference 5) Annual children's camp	• Awareness that they are not alone • Validation of feelings and experiences • Improved self-confidence, positive identity and self-concept • Development of a group identity	1) Experience of personal empowerment 2) Connection with individuals across the country
Advocacy for patients	1) Organize a letter-writing campaign to government 2) Event to attract media attention 3) Provide information on the steps for individuals to assume in approaching insurance companies for coverage of hair pieces	• Patients acquire the knowledge to advocate for their individual needs • Government becomes aware of the insurance issue as it relates to their health care policy	1) Health care policy change 2) Recognition of the medical need for hair-pieces and standard provision of financial support from insurance companies
Public education on alopecia areata	1) Produce a PSA 2) Submit stories of individuals with alopecia areata to newspapers and magazines across Canada	• Recognition of the words 'alopecia areata' • Awareness of hair loss conditions • Increased sensitivity to hair loss	1) Decrease in rude and hurtful comments made to bald people 2) Gain public support for funding initiatives.

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