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The Voices of Albinism

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A Thesis

in

The Department

of

Sociology and Anthropology

Presented in Partial Fulfilment of the Requirements
For the Degree of Master of Arts at
Concordia University
Montreal, Quebec, Canada

August 21, 2001

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ABSTRACT

The Voices of Albinism

Nathalie Wan-Kee-Cheung

Albinism is a rare genetic condition that affects the pigmentation of the retina, hair, and skin. Consequently, people with albinism world-wide experience the stigma and negative repercussions of an unconventional physical appearance as well as a visual disability. The medical literature has focused extensively on the genetics of albinism amongst animals, but it has been relatively under-studied and ignored in sociology. People with albinism have rarely had the opportunity to tell their stories; to tell their sorrows and their triumphs. This thesis attempts to remedy this failure in social science.

In-depth interviews were conducted with 7 women and 5 men, living in various countries globally. The study is framed around Erving Goffman's theory of stigma and "spoiled identity" as well as the more recent Disability Studies that stresses "the normals" as being the "identity spoilers" or the "problem". The participants revealed victimisation from various sources including students, teachers, employers, colleagues, strangers and the medical profession. Focus is placed on the strategies that respondents have devised in coping with the adversities that often accompany a highly visible physical difference and disability. Eight principal methods of reaction and response to the discrimination against people with albinism can be distinguished. These strategies varied depending on the circumstances of the interaction and the informant's coping skills. These typologies are not mutually exclusive and do overlap. They include: (1) *The Defiant* – those who are quick to respond to insults and are forthright in asserting their rights; (2) *The Activists* – those who are involved in heightening public awareness about albinism in a positive light; (3) *The Serenes* – those who patiently explain their condition to others; (4) *The Internalizers* – those who resent mistreatment but internalize and assimilate their pain; (5) *The Talkers* – those who discuss their adversities with family and friends; (6) *The Hiders* – those who hide their disability to escape prejudice; (7) *The Flamboyants* – those who display themselves and publicly reveal their uniqueness; (8) *The Positivists* – those who have learned to accept albinism as a part of their identity.

These eight different types of responses and reactions to resistance to the stigmatisation of albinism are essential elements of personal change and, even possibly, social change. People with albinism have developed these coping mechanisms at various circumstances throughout their lives. This thesis quotes respondents' own words in order to accurately portray the respondents' emotions. Such methodology offers the chance for people with albinism to voice their experiences and for us researchers to listen and learn.

ACKNOWLEDGEMENTS

Many people contributed generously to this project and I am indebted to them. I would first like to express my foremost gratitude to my thesis committee. A special thanks goes to my supervisor, Dr. Anthony Synnott, whose guidance, support, and accessibility proved invaluable. My appreciation is also extended to Pearl Crichton and Dr. Anouk Belanger who offered me insightful comments and input.

I am deeply grateful to all my respondents for sharing their personal lives; their sorrows and their triumphs. In particular, I would like to thank Chris G. for his assistance especially during the first stages of this project.

My heartfelt gratitude goes out to my parents, my brother, Christopher, and my husband, Peter, for their endless moral support. Their belief in me and in the importance of this project has made this experience a memorable one. I dedicate this thesis to them.

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INTRODUCTION

Most people know little about the condition beyond the appearance of persons with albinism. From the Latin word 'albus' meaning white, Oculocutaneous albinism (OCA) is a rare, genetically inherited condition resulting in a significant reduction or absence of pigmentation in the hair, skin and eyes at birth (Kuster, 2000; Oetting, Richard and King, 1996). The lack of pigmentation in albinism results in visual impairment to various degrees as well as milky or translucent skin (Vander Kolk, 1983). People with albinism are often stigmatized and discriminated against because of their unconventional appearance and visual disability. Vander Kolk notes that people with albinism live their entire lives with an insensitive and unaccepting public (1983).

Historically, people with various depigmentating conditions, including albinism, have occupied a spectrum of social positions, ranging from outcasts to semigods (Witkop, 1975). Montezuma, emperor of the Aztecs, maintained a museum of living human biological curiosities; prominent among these were numerous people with albinism. Albinism was viewed as a disfiguring skin disorder, however, not all descriptions of depigmented persons carried this negative connotation. One of the most positive religious statements is the description of Christ in the Revelation 1:14: "His head and his hair were white like wool, as white as snow; and his eyes were like a flame of fire" (Witkop, 1975:1).

In nineteenth-century America, albinism was considered such a bizarre trait that people with this condition were exhibited in circus side-shows. Furthermore, with the advent of the camera, these individuals were featured on postcards which were widely distributed and collected from the 1870-90's (www.lunaeterna.net/popcult/, 1997).

Even today, a plethora of misconceptions about albinism persists. Studies on albinism typically involve scientific research about the complex genetic disorder of albinism. Most studies are conducted on animals, most commonly, rats, rabbits and mice. However, few studies have featured profiles of people with albinism. Thus, little is known about people with albinism beyond their appearance and visual disability.

The Social Meaning of Albinism: Cross-cultural comparisons

People with albinism worldwide experience the negative repercussions of an unconventional physical appearance as well as a visual disability. Due to its rarity, people often hold misconceptions about people with albinism.

Among the San Blas Indians of Panama, people with albinism are called moon-children because they avoid the bright sunlight of day and go about their tasks in subdued light. This has given rise to the folklore that people with albinism “see in the dark”. Among the San Blas, people with albinism are semioutcasts; they participate less in daytime tribal activities and are not permitted to marry (Witkop, 1975:1).

In parts of Africa, people with albinism are treated like outcasts from birth. As white-skinned men and women in a black society, they are shunned and even murdered as they are feared to be products of witchcraft (McNeil, 1997). Libby Young notes that people with albinism in Zimbabwe complain that they are “despised and shunned by other Zimbabweans because of their skin color and...because of society’s uninformed fear that albinism is infections. We are generally treated like second-class citizens” (1996:1).

In North America, the prejudice is also apparent. In a society that considers itself enlightened and striving for political correctness, people with albinism are continually

castigated for their aberrance. Prejudice towards people with albinism is embedded in our society. This is evidenced by the negative manner in which they are portrayed in popular culture, including films such as “Powder” (1995) and “Albino” (1976). Persons with albinism are portrayed as oddities and villains. Hollywood’s tradition of equating albinism with evil (“Albino”) or alien (“Powder”) demonstrates that prejudice towards persons with albinism is socially acceptable.

Vander Kolk and Bright noted that although attitudes towards albinism in the United States are often similar to those regarding other visual impairments, they vary because of the role physical appearance plays in attitude formation. A common attitude of non-albinic students was that “albinism is unattractive and therefore, persons affected by it are ‘freaks’ to be ridiculed” (1983:49). Various misconceptions about albinism by non-albinic students were also found in the study. These include: ‘people with albinism should be avoided because they have a disease’, ‘they are here as a result of evil spirits or wrong-doing’, ‘they are retarded’, ‘they should be placed in the circus when they are children’ and ‘they or their parents are being punished by God’ (Vander Kolk and Bright, 1983:49).

It is apparent that much of the prejudice toward people with albinism stems from fear of an unknown condition. Certain physical characteristics elicit fear because the etiology of the attribute or disorder is unknown, unpredictable, and unexpected (Sontag, 1979). Due to its unfamiliarity, people with albinism are stigmatized and marginalised by societies. As Murphy notes, “the greatest impediment to a person’s taking full part in his society is not his flaws, but rather the tissue of myths, fears, and misunderstandings

that society attaches to them” (1987:140). It seems what gives stigma its intensity and reality is fear of the unknown.

THE RESEARCH PROBLEM

One person in 17,000, in the United States, has a type of albinism (NOAH, 2000 A). Although medical research on albinism abounds, there is little research devoted to the extent to which people with albinism are stigmatized in society. The existing literature on people with albinism focuses largely on the discrimination against people with albinism in Africa and the medical problems that are caused by albinism. Yet, very few studies have featured profiles of people with albinism themselves. This includes the lack of sociological research that delves into the lives of people with albinism.

This thesis proposes to give voice to people with albinism as they recount the negative social repercussions they face in societies that marginalize and stigmatize people with an unconventional physical appearance and a disability, and also how they cope with such discrimination and prejudice.

This study looks at albinism universally. Through my interviews, I try to determine how albinism affects peoples’ lives: during their childhood, with their families, at work, in romantic relationships, with the medical profession, and with the general public. Research was also conducted to determine the coping mechanisms that people with albinism develop when faced with social stigmas.

This study will be framed around Erving Goffman’s theory of stigma and the more recent theory in Disability Studies of visual impairment as a ‘non-visible disability’. Persons with albinism possess a visual impairment than can arguably be considered as a non-visible disability since people who are not aware that persons with albinism possess

a visual impairment are often unable to detect the visual impairment of a person with albinism. The literature on Disability Studies points out that people interact differently towards people who possess a visible disability and with those whose disability is not strikingly noticeable.

The organization of the thesis is as follows: Chapter One discusses a review of the literature documenting medical literature on albinism as well as its existence in parts of Africa. Chapter Two explores Goffman's stigma theory and Disability Studies and its relevance to the study of people with albinism. Chapter Three describes the method of data collection. Chapters Four through Six present the findings. Chapter Four discusses childhood victimisation, family dynamics and intimate relationships, Chapter Five focuses on employment discrimination, the medical profession and public harassment, and Chapter Six discusses the coping mechanisms that the participants have developed.

The quotes in the last three chapters, that present the findings, are lengthy and numerous. This is important in order to allow the respondents to furnish detailed accounts about their lives. I have chosen qualitative research as the method to convey the research findings, as it offers the chance for people with albinism to voice their experiences, and for us researchers to listen.

CHAPTER ONE

ALBINISM

MEDICAL LITERATURE OF ALBINISM

Albinism is a relatively rare genetic disorder. In the United States, 1 person in 17,000 has albinism for a total of about 16,000 individuals (NOAH. "What is Albinism?": 2000 A). The condition is more common among Blacks than among Whites, and almost unknown among Asians (McNeil, 1997). In parts of Nigeria, as many as 1 in 1,100 have albinism and in parts of South Africa the incidence is 1 in 1,800 (McNeil, 1997).

Existing medical literature on human albinism examines the various types of albinism. Albinism represents a group of inherited abnormalities of melanin synthesis characterized by a congenital reduction or absence of melanin pigment in association with specific developmental changes in the optic system resulting from the hypopigmentation (Oetting, Richard and King, 1996). There are two main types of albinism. One type, Oculocutaneous albinism (OCA), affects two regions of the body: the skin and hair and the optic system including the eye and the optic nerves. The second type, Ocular albinism (OA), produces the same changes in the optic system by reducing mainly the retinal pigment of the eye, usually with no clinical difference in the color of the skin and hair (Oetting, Richard and King, 1996). This thesis focuses only on persons with Oculocutaneous albinism.

Lack of Melanin Pigment

The level of visual acuity varies among people with albinism according to the amount of ocular pigmentation present and the level of macular development. People

with Oculocutaneous albinism exhibit less pigmentation than people with Ocular albinism and, therefore, tend to have lower acuity levels (20/80 to 20/400) (Oetting, Richard and King, 1996). The eye needs melanin pigment to develop normal vision. People with albinism have impairment of vision because the eye does not have a normal amount of melanin pigment during development.

Melanin is a dark compound that is called a photoprotective pigment. The major role of melanin pigment in the skin is to absorb the ultraviolet (UV) light that comes from the sun so that the skin is not damaged. In addition to the lack of melanin in their eyes, people with Oculocutaneous albinism do not have melanin pigment in their skin. As a result, their skin is sensitive to the sunlight and they are particularly prone to sunburn and in more severe cases, skin cancer (Oetting, Richard and King, 1996).

In addition to visual impairment, people with albinism may possess other eye problems. The major abnormality in the eye in albinism involves the development of the nerves that connect the retina to the brain. People with albinism have an unusual pattern for sending nerve signals from the eye to the brain. The nerve connections from the eye to the vision areas of the brain are different from the norm. This unusual pattern for nerve signals prevents the eyes from working well together, and causes reduced depth perception. Other eye problems include *nystagmus*, which is an involuntary rapid movement of the eyes back and forth; *strabismus*, which means that they eyes do not fixate and track together (“cross eyes” or “lazy eyes”); and *photophobia*, which is the sensitivity to light (Oetting, Richard and King, 1996).

Visual Acuity

Visual acuity levels for people with albinism range from low vision to legal blindness. Categories such as 'blind' and 'partially sighted' are used for medical and legal purposes (Webster and Roe, 1998:23). Although representing only one aspect of vision, visual acuity is the basis on which an individual's visual impairment is usually categorized.

Tests of visual acuity indicate the resolving power of the eye: the ability to distinguish very fine detail (Webster and Roe, 1998:23). There are a variety of ways to measure visual acuity, but the most common method uses the Snellen Chart. The chart has rows of different size letters arranged in decreasing size, which can be read by a 'normal eye' at different distances. The largest letter has a viewing distance of 200 feet, with smaller letters for distances of 120, 80, 40, 30, 20 and 17 feet (Webster and Roe, 1998:23).

A normal eye reads the letters at the 20 feet mark from a distance of 20 feet. Visual acuity for each eye is tested separately by asking the person to read the letters from a distance of 20 feet with one eye covered. The visual acuity for each eye is expressed as 20 over the smallest line of letters that can be read. In North America, the 'normal' visual acuity is expressed as 20/20.

For example, a visual acuity of 20/80 indicates that the smallest size of letters that an individual can identify is 80 at a distance of 20 feet. Effectively, this means that the individual can see at 20 feet what a person with average eyesight can see at a distance of 80 feet. This is particularly low vision.

Below is a chart describing the various degrees of visual impairment. Visual acuity of persons with albinism range from 20/80 to 20/400 (Oetting, Richard and King, 1996:330).

<i>Category of Vision</i>	<i>Degree of Impairment</i>	<i>Visual acuity with correction</i>
Normal	None	20/20
Normal	Slight	Less than 20/25
Low vision	Moderate	Less than 20/60
Low vision	Severe	Less than 20/160
Legal Blindness	Profound	Less than 20/200

(Webster and Roe, 1998)

Low Vision Aids

Apart from surgery, there are low vision aids that are prescribed based on the quantity and quality of the remaining vision and the goals of each individual. There are advantages and limitations to all the aids, which must be demonstrated and understood for the individual to obtain maximum benefit from the aid.

There are various types of low vision aids: glasses, telescopes for intermediate and distance needs and microscopes and magnifiers for near tasks. Firstly, distance vision improvement can be obtained through the use of a telescope. Telescopes can be hand held and come in various shapes and sizes. They can also be clipped-on to a pair of glasses. Although of various manufacturers and powers, all similar devices produce a clearer view of a distant object. This group of low vision devices is best adapted to short term viewing needs such as reading signs or locating a distant object. For optical reasons, size is kept to a minimum to reduce weight and improve appearance (NOAH, "Low Vision Aids": 2000 B).

There are several mounted telescopes such as the Bioptic telescope, the Bita telescope, and the Behind the Lens Telescope. A new miniature bioptic or Clear View Lens is also available (NOAH, 2000 B).

The Bioptic telescope functions as two optical systems. Viewing through the upper section is through the telescope, while viewing through the lower section is through the optical correction of lenses of regular glasses. In this manner, two optical systems are incorporated into a pair of glasses. The bioptic allows telescopic vision and general vision.

The Bita telescope is also mounted in glasses and uses a much smaller telescope placed in the periphery of the lens. Its advantages include less weight and better appearance since the telescopes are smaller than regular bioptic telescopes. As a result of the decrease in size, a smaller field of view is obtained (NOAH, 2000 B).

Another option is the Behind the Lens telescope, which is placed in the lower section of the lens and off to the left or right. By shifting one's eye to the side, the view of the telescope is apparent. The Behind the Lens telescope is also an effort to decrease weight and improve appearance (NOAH, 2000 B).

In response to increased demand for new and better telescopes, a Clear View Lens was designed. It is a miniature of the Bioptic, which again, extends from the front surface of the lenses of a pair of glasses. It is one inch in length, compared to the three to four inch length of the regular bioptic. It is still focusable and the weight is much reduced. All of these designs are innovative ways for people with albinism to use a telescope to improve distance vision (NOAH, 2000 B).

Near vision aids include microscopes or reading glasses which can be used monocularly or biocularly. These free both hands to hold reading matter or other materials for close work. This type of aid also allows for the widest field of view for reading.

Non-optical aids include a variety of devices such as writing guides, filters or lamps. Writing guides are templates with open areas along the lines to keep writing aligned. Filters use color combinations to increase contrast (such as yellow filter to look at light blue letters). Many people with albinism discover techniques very helpful for themselves and others. In addition, various computers use both software and hardware to enlarge characters on the screen (NOAH, 2000 B).

A closed circuit television (CCTV) provides maximum magnification. The CCTV allows the viewer to adjust various parameters such as size, contrast, and brightness to the person's needs. Reverse polarity allows the letters to appear light on a dark background, in order to reduce glare (NOAH, 2000 B).

Essentially, low vision rehabilitation combines basic optical principles and innovation to enhance the visual functioning of people with albinism who are visually impaired.

Aid for Eye Problems

Ophthalmologists and optometrists can help people with albinism compensate for their eye problems, but they cannot cure them.

For *nystagmus*, research has searched for an effective treatment that helps in all cases. Attempted treatments to control nystagmus have included biofeedback, contact lenses, and surgery. The most promising may be eye muscle surgery that reduces the

movement of the eyes. However, vision may not improve in all cases due to other associated eye abnormalities (Oetting, Richard and King, 1996).

For *strabismus*, ophthalmologists prefer to treat infants starting at about six months of age, before the function of their eyes has developed fully. They may recommend that parents patch one eye to promote the use of the non-preferred eye. In other cases, the alignment of the eyes improves with the wearing of glasses. Correction of strabismus by surgery or by injection of medicine into the muscles around the eyes does not completely correct the problem with both eyes fixing on one point. Although these treatments may improve the alignment of the eyes and enhance psychosocial development and interpersonal interaction, they cannot correct the improper routing of the nerves to the brain (Oetting, Richard and King, 1996).

For *photophobia*, eye doctors can prescribe dark glasses that shield the eyes from bright light. There is no proof that dark glasses will improve vision, even when used at a very early age, however, they may improve comfort (Oetting, Richard and King, 1996).

Genetics of Albinism

For almost all types of albinism, the trait for albinism is passed to an individual from both parents. Since the body has two sets of genes, a person may have normal pigmentation but carry the albinism gene, therefore, the coloring of each parent may not reflect albinism (Oliver, 1999; NOAH, 2000 A). If a person has one gene for normal pigmentation and one gene for albinism, he or she will have enough genetic information to make normal pigment. The albinism gene is "recessive", therefore, it does not result in albinism unless a person has two copies of the gene for albinism and no copy of the gene that makes normal pigment (NOAH, 2000 A).

Each parent of a child with OCA albinism must carry the gene for albinism. If both parents carry the recessive gene, and neither parent has albinism, there is a one in four chance, at each pregnancy, of producing a child with albinism. This type of inheritance is called autosomal recessive inheritance (Oliver, 1999). However, because there is no test that successfully detects the gene in the parents, there is no way of knowing prior to delivery of the baby if the child will have albinism (Oliver, 1999).

ALBINISM IN AFRICA

Black, yet white; people in parts of Africa are shunned because of having albinism. Albinism is more prevalent among Black people in certain countries in Africa than among Whites (McNeil, 1997.) In parts of Nigeria, 1 in 1,100 have albinism; in parts of South Africa the incidence is 1 in 1,800; and The Tanzania Albino Society claims that, in Tanzania, there are 700,000 people with albinism, or 2% of the population (McNeil, 1997 and Economist 22.4.00:50). That seems implausibly high since American researchers suggest that only one in 17,000 people has some form of albinism. One explanation for the large number of people with albinism on the coast is that some coastal communities take a relaxed view of inbreeding, increasing the chance that parents with albinism will pass on their genes(Economist 22.4.00:50).

According to Jennifer Kromberg (1997), an expert on albinism at the South African Institute for Medical Research, the number of people with albinism in Africa varies sharply from country to country and tribe to tribe. For instance, in South Africa it is twice as high among the Tswana as among the Zulu, because the Tswana encourage marriage between cousins while the Zulu forbid it (McNeil, 1997).

In many parts of Africa, albinism has for centuries been viewed as a life-long curse (McNeil, 1997). Among the existing literature on the social and psychological status of people with albinism in Africa, it is clear that there is indeed a negative stigma attached to albinism (Kuster, 2000). Individuals in these races are often ostracized because some believe that God delivered judgement on a family with albinism and that the individual with albinism is cursed, or is the embodiment of sin (NOAH, "African Americans with Albinism": 2000 C). In some religions and societies, people believe this curse.

Within the Songye culture of Zaire, children with albinism are regarded as "bad" children (*malwa*) and are considered inferior to other members of society, not even human beings. They are believed to be supernatural because they are in contact with the anti-world of sorcerers. They come to this world to stay for a short time and afterward return to their own world. These children are given basic care, but all parents expect them to die sooner rather than later, for the Songye believe these children did not come to earth to live but to die. Such children are truly marginal, and hence their interaction with their surrounding world is limited (Devlieger, 1995).

Superstitions are equally strong in rural Zimbabwe. The practice of killing suspected witches survives, and children with albinism were once smothered at birth. In addition, the belief that adults with albinism do not die, but simply vanish, is still widely held. There is also a lingering belief that albinism is somehow contagious. In fact, many Africans admit to spitting when they see a person with albinism, to ward off the "spell" (McNeil, 1997).

Furthermore, it is believed that a person with albinism is the result of incest or inbreeding. The most common myth of today is that the non-Caucasian person with albinism must be the result of a mixed union (Kuster, 2000). Those who hold this view are unaware that people with albinism existed in societies of color before these societies had any contact with Caucasians (NOAH, 2000 C). In general, albinism is equated with, and categorized as a blemish, mark, or stain on the group of people and can stimulate disgrace, dishonor, and shame (Westhoff, 1993). It is a visual stigma that makes people look at albinism with suspicion, and fear.

Realising the importance of dispelling the myths of albinism within African societies, several organizations for albinism have been developed in Africa and have focussed on educating communities about the facts on albinism. In 1998, the Albino Association of Zimbabwe (AAZ) was founded. Its main goal was to educate society about the facts on albinism and to fight the prejudice against people with albinism. They have since had support from the local office of a global sunscreen lotion manufacturer who recently donated several boxes of sunscreen lotion to the association. Several opticians have also donated used glasses (Kuster, 2000).

A similar group in Malawi, the Albino Association of Malawi (AAM), is vigorously campaigning against social discrimination. One of the priorities of AAM is to fight against the belief that people with albinism have a “low brain capacity and thus cannot function at the same level as people without albinism” (Kuster, 2000:2). An AAM spokesperson explains, “we are trying to negotiate with teachers that albinos should be left to learn at the same rate like any other children. We want recognition and acceptance because we are also human beings” (Kuster, 2000:2)

Furthermore, in Zimbabwe, Professor Makumbe has founded the Zimbabwe Albino Trust in the hope of battling the prejudice against people with albinism. His first goals are almost pathetically humble: to raise enough money to buy sunscreen lotion and spectacles for people with albinism who cannot afford them, and to raise \$20,000 for a survey to count the number of people with Albinism in Zimbabwe and to ask them what they need most.

In developed countries, the lack of sunscreen lotion is not an issue amongst people with albinism. However, in parts of Africa where people are hit by the harsh rays of the equatorial sun, skin cancer is prevalent and fatal. According to the Zimbabwe Albino Association, the life expectancy of people with albinism in Zimbabwe is 43 years compared to 57 years for those without albinism. The mortality rate is higher amongst people with albinism because of the prevalence of skin cancer (Machipisa, 1998).

Stigma of skin color

Skin color is both highly visible and highly political (Westhoff, 1993). Historically, ethnic pigmentation favors the lighter-skinned race in social and economic class (Wassermann, 1974). The greater the contrast in color, the greater the likelihood of prejudice, discrimination, apartheid, or conflict for the darker pigmented people ensuing within a community. The stigma of color, or lack of it, can marginalize and can stimulate disgrace, dishonour, and shame (Westhoff, 1993). Thus, “whiteness” is the privileged color globally. However, “darkness” has been marginalized in North America, Europe and the British Empire while, in Africa, “whiteness” or albinism has been marginalized. Hence the reason why albinism is so serious in Black Africa, and less so in Canada.

Pigmentation of the skin has created various problems for many different races. A.H. Richmond (1957) has theorised that color invokes an emotional response, has deep-rooted symbolic significance, and is always associated with objects. Racial or ethnic prejudice requires (1) the existence in a community of two or more groups easily distinguishable from one another on a highly visible characteristic such as skin color, (2) the creation of false stereotyped ideas, and (3) the existence of feelings of insecurity and frustration among members of the in-group (p.124). In addition, I would add inequality and competition.

Vander Kolk and Bright (1983) reported that lack of understanding creates prejudice that can be corrected and reversed through education. Totally forgetting, of course, that education is often part of the problem, and may indeed reinforce racism. In their study, the majority of people without albinism knew little about the facts regarding albinism. Children thought that a person with albinism was merely a child from a mixed race family. Especially among Black communities, albinism is a stigma and separates the individual from the community (Westhoff, 1993). According to Westhoff's (1993) study of albinism conducted in the Dominican Republic, a stigma is associated with the whiteness of skin. Westhoff (1993) noted that the majority of his respondents did not regard their albinism as a social or physical advantage, but as a negative characteristic. They also perceived that others in the community viewed albinism as a flaw of character. Ezelio (1989) described similar findings in Nigeria.

NATIONAL ORGANIZATION FOR ALBINISM AND HYPOPIGMENTATION

The National Organization for Albinism and Hypopigmentation (NOAH) is one of the few organizations aimed at providing information about the social aspects of

albinism. NOAH was founded in 1982, in Philadelphia, and is an all-volunteer organisation. It is a U.S. based non-profit, tax-exempt organisation that offers information and support to people with albinism, their families and the professionals who work with them. NOAH is operated by its members on a volunteer basis and is funded primarily by dues and contributions of its members. The organisation has also received grants from foundations and organisations for specific projects. NOAH's objectives are to provide information and support to individuals and families with albinism, to promote public and professional education about these conditions, and to encourage research and research funding that will lead to improved diagnosis and treatment.

NOAH provides information and support for its members by sponsoring workshops and conferences on albinism. The organisation publishes a large print bi-annual newsletter, NOAH News, as well as various Information Bulletins about albinism. NOAH also maintains an Internet site that includes public bulletin boards for exchanging information about albinism. The site also gives people with albinism the opportunity to express their feelings and emotions by exchanging messages with people who share and understand their medical condition. Furthermore, NOAH educates the population about albinism and works to improve attitudes towards those with the condition through television appearances, newspaper articles, information packets for libraries, and outreach to professionals. NOAH also networks with support groups for people with albinism in other countries, and promotes development of albinism support groups throughout the world through participation in the Albinism World Alliance (NOAH, "About NOAH": 2000 D).

CHAPTER 2

THEORIZING THE STIGMA OF ALBINISM

The studies cited in the previous chapter indicate that albinism is a highly stigmatized condition. People with albinism experience rejection from multiple sources and clearly constitute a stigmatized group. Erving Goffman is the principal theorist on stigma, and his work will be discussed below. Although Goffman does not discuss in depth the particular question of albinism and stigmatization, his accounts draw on the plight of people with disabilities. Since people with albinism possess a visual impairment, Disability Studies will also be examined. Disability Studies have theorized the notion of “non-visible disability” versus “visible disability” which has been proved to be an important distinction for my respondents, and has also shifted emphasis from the locus of stigma in Goffman to the stigmatizing process; from the stigmatized to the stigmatizers.

ERVING GOFFMAN

Cognitive and perceptual processing of human body differences is universal. However, when particular human differences are evaluated negatively and viewed with negative moral meaning, the basis for stigma is created.

In his classic study *Stigma: Notes on the Management of Spoiled Identity*, Goffman makes disability a sociological topic in that he speaks of societal reactions to “abominations of the body”. He suggests that all human differences are potentially stigmatizable may be devalued by wider society. For Goffman, stigmatized persons possess “an attribute that is deeply discrediting”. He distinguishes between three basic

types or forms of stigma: (1) "Abominations of the body" which include various physical deformities, as well as conditions such as blindness and deafness. (2) "Blemishes of individual character" inferred from a record of "mental disorder, imprisonment...and addiction." (3) "The tribal stigma of race, nation and religion". Thus many different aspects of human practices and appearances fit under the umbrella concept of stigma. The stigma can include any other qualities the person may possess: "...an individual who might have been received easily in ordinary social intercourse possesses a trait that can obtrude itself upon attention and turn those of us whom he meets away from him. breaking the claim that his other attributes have on us. He possesses a stigma, an undesired differentness from what we had anticipated" (Goffman, 1986:3, 4).

Goffman refers to the others who possess the potential to stigmatize people as the "normals". Normals are those who have many different attributes but who do not, in the interactional situation in question, have an attribute of difference. Normals are those who, at least in the face of some individuals and within some interactional situations, do not represent "undesired differentness." Apart from utilizing stigma terms to further demoralize the stigmatized, the normals have a tendency to "impute a wide range of imperfections on the basis of the original one". In fact, the stigmatized individual is often viewed as less human and is more likely to suffer a variety of discrimination which could reduce his or her life chances (Goffman, 1963:5). This is known now as the "horns effect" (Synnott, 1993:74). In studying the power of beauty and ugliness in society, Berscheid and Walster, and Synnott, maintain that the impact of physical appearance is present everywhere. The "horns effect" has its corollary, which researchers describe as the "halo effect". Students agreed that beautiful people were generally more sociable.

kind, exciting and interesting than less attractive people (1972:74; 1993:74,77). Moreover, attractive children were found to be more popular among their peers; and teachers as well as parents had higher expectations of attractive people.

Goffman distinguishes between the *discredited* and the *discreditable*. The *discredited* are those stigmatized individuals who assume that his or her differentness is known about or is readily apparent to others. The *discreditable*, on the other hand, are attributes that are not readily apparent and, therefore, stigmatization may not result. Persons with discreditable traits, for instance ex-convicts, fear that their secret will be revealed and will take steps to protect themselves from exposure. The management of undisclosed discrediting information about oneself is what Goffman refers to as "passing" (Goffman, 1963:42). "Because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent" (Goffman, 1963:74).

Goffman contends that "visibility" of a particular stigma is a "crucial factor" when determining whether an individual is to be stigmatized against or not (Goffman, 1963: 48). Attributes such as skin color and particular physical disabilities provide visible evidence of stigma, so their bearer can be immediately discredited. The more prominent the stigma, the more likely it will effect the individual's social interactions. Since the normals assume that the stigmatized are abnormal, it is obvious that "acceptance" is "the central feature of the stigmatized individual's situation in life" (Goffman, 1963:8). How does such an individual respond to the devastating consequences of what Goffman calls "spoiled identity"?

While the visibility of some stigma preclude the option of passing, some discredited traits can be “covered” and “concealed” (Goffman, 1963:102). One type of covering can be done by literally by wearing dark glasses to conceal the evidence of facial disfigurement, in the region of the eye, due to blindness. Another type of covering involves an effort to restrict the display of disabilities identified with the stigma. For instance, a visually impaired person who can only read a book by bringing it very close to the eyes may hesitate to read around others. Similarly, a blind person will learn to look directly at the speaker even though this looking accomplishes no seeing. This prevents the blind person from diverting off into various directions or otherwise unknowingly violating the attention cues though which conversations are organized (Goffman, 1963:103,104).

Goffman does allow for the possibility that some discredited traits can be reversible or overcome through plastic surgery or medical treatment, for example. However, they may be victimized by fraudulent claims, and even if their efforts are successful, they are not likely to be considered truly “normal”. They instead “used to have” a particular blemish, and have now “corrected” it, but the stigma lingers (Goffman, 1963:9). In the case where individuals do not have the options of plastic surgery, for example, then the individual can compensate by stressing achievements in other activities and areas of life.

Stigma of Albinism

Goffman is insightful about the visually impaired and blind people; indeed people with albinism have a condition that Goffman would deem a stigmatized condition. In fact, people with albinism have a double stigma: the color of their skin, and their visual

impairment. Both are “abominations of the body” that elicit immediate negative assessment from others on the basis of aesthetically displeasing qualities. However, as the blemish is so visible, management of the stigma of albinism is difficult. Persons with albinism cannot cover all parts of their body to disguise their skin color, as clothing can cover only so much. Thus, people with albinism are *discredited* as their physical differences are readily apparent to others.

Due to the discrimination some of my respondents have endured in relation to their visual disability, they hesitate to read around others. When reading a book, people with albinism must bring it very close to the eyes. According to Goffman (1963), such behavior allows the person with albinism to “cover” or “conceal” his/her discredited traits (p.102).

The stigma of albinism is mostly present when persons with albinism interact with people who are unaware of the genetic condition. However, those who are knowledgeable about albinism, will view it as an immutable condition. Therefore, they will understand that it is not within an individual’s power to change.

Since the publication of Goffman’s classic text, the conditions that evoked negative reactions toward people, such as those with physical disabilities, have changed considerably. There is a growing effort with increasing mainstreaming and political lobbying to integrate people with disabilities into the larger society. The groups that Goffman described four decades ago have now, at least in principle, been given legal rights to a full participation in society. For instance, the Canadian Charter of Rights and Freedoms guarantees the rights of people with disabilities.

The Charters states:

Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, color, religion, sex, age or mental or physical disability.

Thus, according to the legislation in Canada, it is against the law to treat someone unfairly because they have a disability. The Canadian Charter of Rights and Freedoms sites an example of this: “It is illegal to refuse to rent an apartment to a person, hire them for a job or serve them in a store because of their disability.” The Canadian Human Rights Act as well as the human rights codes in each province and territory also protects the rights of people with disabilities.

Similarly, the Americans with Disabilities Act (ADA) was enacted, in the United States, in 1990 to prohibit discrimination against persons with disabilities in areas such as employment, public accommodations and housing. The ADA’s broad scope prohibits discrimination on the basis of actual disability and the employer’s perception of disability. The ADA states the following:

The ADA gives civil rights protections to individuals with disabilities similar to those provided to individuals on the basis of race, color, sex, national origin, age and religion. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, State and local government services and telecommunication (1990).

However, despite these efforts, individuals with physical disabilities continue to experience various forms of devaluation and discrimination.

Even within the English language, the word “albino” creates a reality that is often unfavorable. It is considered dehumanizing to refer to a person in terms of a condition. To call someone an “albino” reduces the potential of that person’s human nature to a biological anomaly. Eloquently stated by one of my respondents, “I have a condition

called “albinism”, I am not an “albino”. It is, therefore, important to refer to a “person with albinism” rather than “albino”. “Person with albinism” puts the person first and the condition second.

DISABILITY STUDIES:

Research in the field of disability has evolved as a way of addressing how people with disabilities have been treated historically and how they continue to be treated. From around the 1920’s, the policy and research agenda in disability was driven by the medical model, in which people were seen as sick and in need of a cure (Rioux, 1994:2). The medical model of disability played a role in the segregation of people with disabilities, and in the labeling of these individuals often as aberrant, deviant, or contaminated, and certainly as abnormal. As such, researchers argue that the medical model has discouraged full citizenship for people with disabilities (Monaghan, 1998:15). The medical model of disability focuses on impairment rather than the person, and within this model, power resides with the medical professions. Based on the traditional medical model, the social problem of disability is founded on the impaired and thereby deviant characteristic of the individual body which is, therefore, understood as vulnerable and dependent rather than on the stigmatizing society (Hughes, 1998:76).

Then in the sixties, disabilities began to be seen through a sociological model which focuses on the stigmatizing process (e.g. Goffman, 1963) and through a psychological model where their experiences have been individualized and pathologized (Harris and Lewin, 1998). This latter approach envisions disability as a physiological problem or a set of unfortunate individual circumstances in need of solutions offered by medical interventions or social work. Brendtro, Brokenleg, and Van Brockern have

described how, at different times, and in different cultures, disability has been viewed and treated as something that is a societal problem, rather than a different way of living (1990). Variations of the popular cultural voice on disability perceived disability as misfortune, as sickness, as “other”, as punishment, and as a threat (Woodill, 1994:209).

However, more recently people with disabilities are being viewed through different perspectives. The new Disability Studies movement from the eighties offers a conceptual framework whereby disability is viewed as a social construct. The sociological model of disability stresses a framework for understanding disability as resulting from the effects of society geared towards able-bodiedness as the norm, rather than a person’s physical, sensory or mental impairment (Hughes, 1998:77). Abberley notes that the concept of oppression is useful here because using that term helps us to understand how social forces have been gathered to discourage individuals with disabilities from exercising their rights. In Abberley’s view, this oppression is the result of historical workings, and therefore can be changed by societal action. This new sociological model fits the experience of many people with disabling conditions, especially non-visible disabilities, and has, therefore, become prominent in the field (1987).

Disability, viewed as a social construct, is now considered a culturally constructed minority identity: a political, aesthetic, and ethical concern; and a universal human experience. Although Disability Studies does not deny that there are differences, either physical or mental, between people, they argue that the nature and significance of these differences depend on the manner in which we view and interpret them (Bogdan and Taylor, 1994). Therefore, instead of seeking to ‘fix’ a person or to detach him or her

from the rest of society, Disability Studies perspectives tend to problematize society rather than the individual (Harris and Lewin, 1998). The solution, therefore, lies not in the person with the disability, but in the persons without the disability, and in removing the barriers that limit people with disabilities participating fully in their communities and in society in general. As Morris notes, "It is not the inability to walk which disables someone, but the steps into the building." (Morris, 1991:10).

The new Disability Studies is about inclusion and also power. In this framework, eliminating social and physical barriers that create disability and promoting social well being are priorities. It identifies ways to increase individual control over social well being, rather than defining social well being as the absence of disability (Rioux, 1994:5). It is clear, then, that there has been a shift from Goffman's theory of "spoiled identity" whereby people with disabilities are stigmatized by the "normals", to the Disability theory of "identity spoilers" who are the ultimately, the "normals". The new Disabilities Studies, therefore, not only calls for the inclusion of people with disabilities into mainstream society, but it also aims to introduce into literary and language studies a perspective that will reveal a pervasive presence that has largely been ignored or misrecognized (Thomson, 1998:1).

INVISIBLE DISABILITY:

People with albinism's visual impairment can be considered as a non-visible disability. Non-visible disability implies that the condition "can be seen if only one would look and discover it" (Matthews, 1994:7). People who are not aware that persons with albinism possess a visual impairment will be unable to detect the visual impairment of a person with albinism easily. Only if one were to look carefully, would one be able to

notice the eye problems that persons with albinism possess, such as *nystagmus* (an involuntary rapid movement of the eyes back and forth) and *strabismus* (eyes do not fixate and track together).

Most of the research into disability typically focuses exclusively on the visibly disabled. Studies have found that people with visible disabilities experience hostile feelings, stereotyping, and avoidance from able-bodied others (Matthews and Harrington, 2000). Those researchers who did consider non-visible disabilities tended to find similar results when the non-visible disabilities are revealed (Asch, 1984). Researchers, however, have tended to neglect the experiences of people who have non-visible disabilities.

To address this omission, Matthews (1994) conducted a pilot study to investigate the use of private boundaries by persons with non-visible disabilities. The study showed that most people with a non-visible disability did not disclose their disability unless they had to. She also found that people with non-visible disabilities felt that disclosure would elicit unwanted sympathy, invite judgement, and damage existing relationships with people who might not understand their disability and, most significantly, might not find them believable (p. 408).

Since the visual impairment of people with albinism is not distinctively visible, people who are unaware of the condition often do not realize that persons with albinism possess this disability. Often times, this can lead to unpleasant encounters with others. My respondents explain their experiences.

My vision is 20/200. Many people don't even realize that I'm visually impaired. They're like "No, you're not. You can't be." The biggest thing I get is "you can't have Albinism because your eyes aren't pink or red." And then they'll see if they look in a certain light. Then they'll be like, "Oh my gosh! You're eyes are glowing red!"

-Christa, 17-

Lots of times, I don't recognise people. And when people don't realise that I can't see, they think that I am a snob for not acknowledging them when I pass by.

-Julie, 25-

The worst part for me would be when people don't understand what albinism is so, in return, they give you a hard time or put you down. My self-esteem has been shattered many times.

-Amy, 21-

There's this misconception that people either have perfect vision or are blind. Therefore, the people in between are stuck...I've had people who did not believe that I was visually impaired. Once, this guy at the bank actually asked me to show him my identity card."

-Chris, 18-

I must have been twenty years old and I went into a small store to buy a book. I asked the employee of the bookstore for the book I wanted. He said, "It's right there, can't you see?"

-Louise, 49-

Some of the misconceptions are that people think that Albinism is a disease that they can catch...They think that the only thing is white hair and white skin and they don't realize that there is any kind of vision problem associated with it.

-Christa, 17-

These quotes vividly illicit the insensitive remarks made by others as a result of their unawareness of the respondents' visual impairment. Respondents reported that they often found themselves explaining their albinism and low-vision as it was not always visibly apparent to others. Even after having disclosed their visual impairment, the participants explained that some people would still not believe them. This type of behavior indicates that people with albinism often experience unsympathetic treatment and remarks from others, due to their non-visible disability.

CHAPTER THREE

METHODOLOGY

An examination of the research on people with albinism shows a lack of research on the social aspects of people with albinism from their perspective. People with albinism have rarely had the opportunity to tell their stories: to tell their sorrows and their triumphs. My thesis attempts to remedy this failure in social science.

Sample Recruitment

Twelve people, 7 women and 5 men, participated in this study. Only one person was known to me at the beginning of the process. As he was a member of the National Organization for Albinism and Hypopigmentation (NOAH), he was able to put me in contact with a few of the respondents. In recruiting the other participants, my sampling design was conducted in a snowball fashion whereby I asked each interviewee if he or she knew someone else with albinism who would be interested to talk with me. I also contacted the Montreal Association for the Blind (MAB) for respondents. The MAB referred me to a few people that they knew who had albinism.

Since albinism is a rare condition, searching for participants with albinism was a relatively difficult task. Many interviewees were the only ones in their family who had albinism, and few socialized with people with albinism as they did not live in a community where there were others with albinism. The only occasion when they do meet others with albinism is the conference held by the National Organization for Albinism and Hypopigmentation every two years. Many interviewees mentioned a person that they had met during the conference and suggested that I contacted them.

Characteristics of the Sample

The participants ranged in age from 17 to 51 years, with a mean age of 33 for the women and 35 for the men. Since many of the participants had previously attended NOAH conferences, they had met people with albinism spanning across the globe. Therefore, I have respondents from Canada (Montreal, P.E.I., Saskatchewan, and Quebec city), the United States (Connecticut and Washington D.C.) and Australia (Sydney).

Ten of the twelve respondents were the sole members of their family to have albinism. Only two people has siblings and a parent who has albinism.

The table below represents the personal characteristics of the respondents.

Name	Age	Sex	Residence	Visual Acuity	Occupation	Marital Status
Christa	17	Female	P.E.I., Canada	20/200	Student	Single
Chris	18	Male	PQ, Canada	20/120	Student	Single
Matthew	19	Male	PQ, Canada	N/A	Student	Single
Amy	21	Female	B.C., Canada	20/200	Mental health worker/Home counsellor	Single
Julie	25	Female	Saskatchewan, Canada	20/500	Graduate student	Single
Kim	30	Female	Sydney, Australia	20/120	Social Worker in mental health	Single
Chantal	44	Female	PQ, Canada	20/200	Human Rights Promotions Officer	Married
Virginia	45	Female	Colorado, USA	20/100	Writer, Artist and Web Designer	Single
Tyrone	42	Male	Washington D.C., USA	20/140	College Administrator at Howard University	Divorced
Bergess	43	Male	Connecticut, USA	20/200	VP Marketing	Divorced
Louise	49	Female	PQ, Canada	20/200	Quality Control Agent	Single
Tommy	51	Male	Washington D.C., USA	20/200	Public School Educator/ Musician	Married

The visual acuity of the respondents ranged from 20/100 to 20/500. 20/200 is considered legally blind (Webster and Roe, 1998:23). Of the twelve respondents, eleven wear prescribed eyeglasses. All the participants use other vision correctional devices including monoculars, magnifiers, laptops with large print software (ZoomText), large print books, CCTV, and bioptic equipment. They do not use a white cane.

Procedure

Since it was my intention to provide my respondents with the opportunity to furnish detailed accounts about their lives, I chose open-ended, semi-structured interviews as my method of data collection rather than rigidly constructed questionnaires (see APPENDIX for sample). Semi-structured interviews also provided the latitude to probe more pertinent topics more deeply. The questions revolved around three main themes: the participants feelings about having albinism; the experiences and adversities they faced in areas such as school, romantic relationships, the medical profession, public places; and the coping mechanism they may have undertaken to deal with the stigma of physical difference and visual impairment.

The interviews were conducted in the summer and fall of 2000. At the beginning of each interview, the nature and objective of the research was explained to each respondent. For the purpose of documenting the interview content, each respondent was given the choice of using his or her real name or choosing a pseudonym to remain anonymous. It is important to note that all the respondents insisted that their real names be used as they felt it was important that their life experiences with albinism be told and known to others.

Two interviewees in Montreal agreed to meet with me personally. However, the remaining 10 respondents all lived in other provinces and countries. Therefore, due to the limitations of financial resources, arrangements were made to interview them by telephone or e-mail. Of the ten living outside Montreal, three interviewees sent me their responses via e-mail as they said that they needed time to think of their answers.

The face-to-face and telephone interviews were tape-recorded and were later transcribed verbatim. The interviews averaged one and half hours in length and all were conducted in one session. Consistent with the qualitative research tradition (Babbi, 2000), the transcripts were then analysed and reviewed for common patterns, themes and topics.

The respondents were extremely generous with their time, and were very open when sharing their recollections. Many mentioned that they had not previously given much thought to the issues on which they were questioned. However, they felt it to be a useful experience. As Matthew pointed out, “this interview is actually good therapy!” Many of them were curious as to why I had chosen to conduct a research on people with albinism, and were thankful that I had decided to devote my efforts into researching the social aspects of albinism.

I found this experience to be extremely illuminating and rewarding. A number of works on people with disabilities as well as people with albinism, indicate the prejudice and discrimination against people with albinism up to and including, in the past, murder. (Possi, 1989; Scott, 1999; Vander Kolk and Bright, 1983; Westhoff, 1993; Witkop, 1975). Yet, their stories of determination and optimism were tremendously moving and

inspiring. In spite of the adversities they have faced, they have developed ways of overcoming them.

Methodological Limitations

I do not claim to have a random or representative sample of the population studied, as the intention of this research was to generate ideas for future research on the social aspects of people with albinism. I listened to a small number of people from whom I was able to gain as much data as possible with regards to the social dimensions of people living with albinism. In studying a small number of individuals, the percentages cited are based on a non-representative and non-random sample. Therefore, the conclusions drawn from this research cannot be generalised to the larger population of persons with albinism.

The objective of this study was to provide an overview of the adversities that people with albinism face, and the mechanisms they develop in dealing with them. Thus, this study should be viewed as an exploratory study. Due to the limited amount of sociological research on people with albinism, future studies need to be conducted utilising larger samples. I recommend that other researchers explore this under-studied and often ignored domain.

CHAPTER 4

IDENTITY, FAMILY, CHILDHOOD, AND INTIMACY

This chapter documents the stigma of albinism and how it can infiltrate every area of a person's personal life: identity, childhood, family and intimacy. The chapter focuses on the respondents' feelings towards albinism, patterns of victimisation during childhood and adolescent years, an analysis of family as a haven, and finally, the challenges of intimate relationships. We begin with what albinism means to them.

IDENTITY

Most of the respondents described albinism as a condition that allowed them to be different and somewhat unique from the rest of society. Although they each held differing views regarding what albinism meant to them, there was a commonality in that they felt that albinism has positively contributed to their identity. Albinism was regarded as “novelty”, “genetically inconvenient”, “special”, “me”, “not different”, and as a source of “pride”.

Despite Goffman's and Disability theorists' claims that people with bodily abominations are stigmatized, it is important to highlight that my research suggests that people with albinism do not perceive themselves as disabled. My respondents have powerfully articulated that albinism has not been a hindrance, nor has it largely limited their ability to function normally. Their life experience as people with albinism has strengthened them; enabling them to triumph in their daily endeavours.

Albinism as “genetically inconvenient”

Most respondents refused to consider albinism as a disability. Rather, they regarded their visual impairment as an inconvenience while being aware of its genetic disposition. Many expressed their desire to drive a car, yet were unable to do so due to their low vision. Chantal brought to light one of the genetically related concerns that some people with albinism hold. That is, a person may want to verify if their spouse is a possible carrier of the recessive gene, for albinism, before having children. The respondents were quick to point out that these issues, however, were merely inconveniences and were not excessively distracting to their lives.

To me, personally, albinism has never been a disability. It's just that I look different but that's all. I've always accepted myself. I'm a very happy person. I was good in school and I always did whatever I wanted, except drive a car. So, to me, albinism does not have an impact. But...different ages has its different worries for various reasons and ...when you want to have a family then, you know, you really have to look at genetics and see if your husband is a carrier or not. These are things that other people wouldn't have to think about.

-Chantal, 44 years-

I've fully accepted it in a sense that this is who I am. I think that I've mentioned to people that if I were not to have albinism I would be a different person, and I don't know what that would be like. My life is complete because of the albinism. There are some inconveniences, namely the visual inconveniences, but other than that, I haven't really found any other things to be overwhelmingly distracting to life.

-Tyrone, 42 years-

Albinism as “me”

Some members of the sample felt a sense of ownership and attachment to their albinism. Having learned to be contented with their physical differences, they regarded albinism as a part of their unique identity. They have learned to accept the physical and

social repercussions that come with having a non-conventional appearance. Bergess describes how albinism has become a part of him:

After 43 years here on earth, it has become "me." At times I don't even think about it, at times it gives me an advantage and at times it can be the worst curse. All in all it is part of what makes me 'me', and 'me' unique. And in the end, I like to be unique.

-Bergess, 43 years-

Albinism as “novelty”

Some respondents explained that albinism was a condition that was unfamiliar and often foreign to others. The respondents acknowledged that they were the sole members of their family to have albinism. To many, they were strikingly different and possessed unusual physical traits. Strangers were sometimes fascinated by their appearance and genially complimented them, while others merely stared out of curiosity.

Julie explains her view of albinism as novelty:

There is no question that albinism makes me different from other people. It means that I stand out in a crowd, and that people notice me. It means that I don't look like my family, and that when I go places, people sometimes stare or do a double take. Having albinism means that I am constantly reminded to put on sunscreen, sometimes by total strangers. Albinism means that I don't see well - that I can't read notes on the board, numbers on the front of the bus, or signs in the airport, without some kind of optical aid. It also means that, lots of times, I don't recognise people. And when people don't realise that I can't see, they think that I am a snob for not acknowledging them when I pass by. Having albinism means that I have a certain amount of local fame. I grew up in a suburb outside of Halifax called Sackville, and was known around the area as "the Sackville Albino". I was often mistaken for... a girl who lived in a neighbouring town and who was known as "the Bedford Albino". I think that I know most of the albinos around my age in Nova Scotia. There have been people who were particularly fascinated by me. Having albinism means that you are sometimes a novelty to people, and they are curious about you. I think it is very important to say that I have not once wanted to wish away my albinism. That is honestly the truth. Having albinism has definitely contributed to who I am. I like who I am, and know that I would have become a completely different person if I had not been born looking this way. Sometimes I have wondered what I would look like without albinism. I have wondered what I would look like with the brown hair, light blue eyes, and freckles that I probably would have had otherwise. However, when I imagine that

person, it's someone who I don't even know. It makes me realise how much of my identity I have tied to what I look like.

-Julie, 25 years-

Albinism as a source of "pride"

Albinism was a source of pride for those who indulged in their differences. They attributed their accomplishments and their compassion to help people, to albinism. The respondents fervently believed that the hardships they have endured have made them emotionally stronger. Kim is proud of her uniqueness:

I am proud of the fact that I am different. When I was little I always hated it because I was teased quite badly, especially in high school, but now I believe it is a blessing in disguise because I am the perfect person, having albinism myself, to be able to educate others on the condition. It also puts me in a great position to be able to support others with albinism, especially young people, and show them that having albinism can be cool and that there is a life after school and you can do anything in life you want to do, within reason. In terms of its importance or meaning on my every day life, I would have to say that on a day to day level it means absolutely nothing. I don't feel as if people look at me as I am in any way different. I have many good friends, a wonderful fiancé, and a career where I am respected for what I do and not how different I may look in certain ways. I am a social worker in psychiatry...I don't see myself as my condition at all, it is hardly an issue, I have a condition called "albinism", I am not an "albino", but I don't have any hang-ups about it either. I am more than happy to answer any questions anyone wants to ask about it. I welcome questions, actually.

-Kim, 30 years-

Albinism as "special"

Along with pride, albinism was regarded as being a special part of the respondents' identity. To those participants, albinism was something exceptional as it made them everything but ordinary. They stood out in crowds and were often centers of attention. For Virginia, albinism is a special gift:

I feel that albinism is one of the most beautiful anomalies on earth. I can't shake the feeling that I was given a choice before birth, and this was it. It's not a disease or a

sickness. It is a color phase that happens naturally in evolution. My albinism has always been special to me. I have looked at it as a gift and a sign that I was different inside and out, not that I feel better than or superior to anyone else. It's hard to explain. I have always been proud of my albinism. I knew it would somehow keep me from blending into the environment I grew up in, and keep me from the path of the welfare mother role I saw all around me. I had more respect for my body in those terms. I don't like blending in being ordinary. Other kids were piercing every part of their bodies, coloring their hair funny colors and doing outlandish things to get attention. I just had to sit quietly or walk down the street or walk into a building.

-Virginia, 45 years-

Albinism as “not different”

Not everyone sees themselves as different, however. A few respondents explained that they scarcely reflect about their albinism. They do not consider albinism to be a disability and they do not distinguish themselves from others. To them, albinism is a non-issue. Chris and Matthew relate their view of albinism:

Generally speaking, I don't refer to myself as a person with albinism. I don't really see it. I just go through life saying that I'm “me”. It always takes a concerted effort to look back and say... “I do fit into that little category”. So for me, it's something that has defined me, but it's not something that I think of on a daily basis. I'd rarely sit on a bus and say “hey, I'm different from all these people”. That doesn't trigger in my mind.

Although I am very active in the disability community, I don't see albinism as a disability. I see my visual condition as somewhat of a disability, but more of an impairment.

-Chris, 18 years-

To me, it's not really anything much besides a visual handicap. I don't think it makes me really any different from anyone else.

-Matthew, 19 years-

“I have a condition called ‘albinism’, I am not an ‘albino’” Kim explains. Being viewed as a ‘person with albinism’ rather than an ‘albino’ looks at the person first and the condition second. This is a message that many of the respondents expressed. Albinism was regarded as positively contributing to one’s identity. From albinism as “novelty”,

“me”, “special”, and a source of “pride”, to being “not different” and “genetically inconvenient”, it is evident that participants related the notion of their identity to the construction of their special bodies.

Although many respondents expressed their visual impairment to be an inconvenience at times, they did not consider it to be a disability. They claimed that having albinism, with its various physical and social repercussions, has contributed to the fact that they are compassionate and internally powerful people, living extraordinary lives. Hence, “any construction of the body...is also a construction of the self as embodied; and, as such, influences not only how the body is treated but also how it is lived” (Synnott, 1993:37).

FAMILY DYNAMICS: “Everyone here loves you”

All my respondents recall home and family being a safe haven. They described family members as being very supportive of them and spoke of loving and accepting parents and siblings. Their immediate families were understanding of their physical differences and visual difficulties and often encouraged them to participate in activities that other children were a part of. Many interviewees felt that their parents were essentially the single force that helped them understand and accept him or her self.

My mother always told me, “when you are inside this home, everyone here loves you, but when you step over the threshold, there’s a world out there that does not and may not”. And she was right and I understood that. That was the way I was raised, to enjoy the opportunities that my family presented to me and, of course, understand later that the world was very cold.

My mother and father loved me dearly. My mother’s sister, my aunt, my grandmother raised me up until I was five. They all gave me nothing but love and encouragement and a lot of support....My parents, if it wasn’t for what they had done for me and how they

prepared me for things, I wouldn't have been able to have come up this way that I am now. I've been able to do a lot of nice things, have wonderful experiences...

-Tommy, 51 years-

My family treats me like everyone else. Everyone knows about my condition but that never ever stopped them from treating me like everyone else. My mom made sure that I became very independent. I asked for help when I absolutely needed it. My family is very supportive and would do anything for me.

-Amy, 21 years-

I think my family has grown with it. I remember talking to my mom about it and she really didn't have any information when I was born. She did not get any kind of real information from physicians.... I think her primary goal was to protect me and to shelter me. I spent, maybe, my first 5 or 6 years with my grandparents in rural Virginia. That helps because they just treated me like all their other grand kids. So that has helped me to really add to everything they did. They were very supportive. I think my mom was very supportive as much as she could be, not really having had any information.

Maybe one time or two a sibling might have been a little bit embarrassed around their friends with me. But by and large, they were very protective and supportive. My relatives, I think, they too have been very proud of me...I never experienced any isolation or separation.

-Tyrone, 42 years-

My immediate family is really accepting because they are in the same boat as me...Most of my extended family is pretty good, especially on my father's side because they grew up with it. My mother's side on the other hand, is a little more nervous. We were in Cape Cod, and our aunt was all worried that we'd get totally burnt to a crisp, which some of us did. She was very concerned. My grandmother is also very nervous...She's still a little concerned and she'll worry about us. The visual issue also comes up there. She'll be concerned at that point. Once she sees us outside playing baseball, it scares her. My uncle, on my mom's side, is actually pretty good. He's very encouraging. We're one of the gang...He's very accepting in that way. He doesn't seem to see the difference either.

-Chris, 18 years-

My parents couldn't be more tolerant and accepting. I've never met anyone who was more tolerant. They're all very supportive.

-Matthew, 19 years-

It took my parents a while to figure that I had albinism because I was born pretty much totally blind and they just thought "oh, she's blind and she's really really fair skinned."

And then my mom thought, "No, there's something different" because I started to see shadows and things sort of got a little bit better. When they realized that I did have albinism, they were thankful that it wasn't something really severe. They were like "Oh, this is good."

-Christa, 17 years-

I was an only child and my parents never treated me any differently than any other child. They always encouraged me to do anything other kids did, I just had to look out for the sun. They got me all the visual aids I needed at school but never made a big deal of it. Mum always said that before I was born she would ask for a "blue eyed blond, something special" and that is what she got. It was never an issue for them. When I insisted on a bike I got one at age 9, I knew they worried but they never stopped me from doing anything other kids did. They were always open about my albinism to me and spoke about it with pride rather than like it was some sort of mutation or disability. The self consciousness I had as a teenager came from the other kids at schools on their perception and judgement of me, not the way my parents made me feel about myself.

-Kim, 30 years-

There was a good balance between my parents. My father was the type who would say, "let's go, you can do it." My mother was more on the protective side and would say, "be careful." It was perfect for me as I could find a good middle ground. I was given both motivation and understanding whenever I failed.

-Louise, 49 years-

I only experienced positivity from my family... Right now, my family is very supportive. My mom has always lectured me about how my little brother looks up to me. My family and relatives all brag about me, and my younger cousins think that I'm cool and like it when I hang out with them. When they were little my cousins thought it was cool when we realised that my hair was almost exactly the same colour as Barbie doll hair. I am sure that my albinism has been discussed, but never with me. I am honestly treated no different because of it. I am one of the more successful, adventurous grandchildren in the family, and people always ask about me and want to know what I am doing. I think that part of it is just because everyone was prepared for the worst, and I have done well - better than a lot of people who don't have a disability.

-Julie, 25 years-

This positive attitude, I think it all comes from your family. How you were raised. It all comes from there...My parents knew nothing about albinism. All they knew was that I had a vision-impairment and that was it. And that I couldn't go in the sun because my skin was very sensitive to the sun and that was it. But everything else was normal.

When I was 13 months and the doctor told my parents "let her go...don't keep her away from doing things and going here and going there. She'll determine her own limits." I mean, it all starts there...Like they said, "if she falls down the stairs too often, she will be much more careful when she gets closer to the stairs." And I think it's true, you will really determine your own limits.

-Chantal, 44-

Although only one of the twelve respondents' parents has albinism, all of the parents are very accepting of their child's condition. Many of the respondents mentioned that when they were born, their parents were not highly informed about the causes and effects of albinism. Yet, they expressed emotions of support and acceptance. For instance, when Christa's parents were told that her visual impairment was caused by albinism, their immediate reaction was, "Oh, this is good."

All of the respondents' immediate families are proud of who they are and their accomplishments. As Julie pointed out, "I am one of the more successful, adventurous grandchildren in the family...." Despite their visual impairment and physical differences, respondents reported that their family "don't seem to see the difference" and treat them as "one of the gang". When Amy's parents discussed her albinism with others, she remembers that they "spoke about it with pride rather than it was some sort of mutation or disability."

All the respondents received endless support from their parents and siblings, however, relatives were not as accepting of the respondent's albinism. In Christa's case, her relatives were insensitive about her condition and made offensive remarks in relation to having albinism.

My uncle was actually the worst person. He told my mom, when I was sitting there, that I shouldn't be allowed to have kids and that my mother shouldn't have had any more. And my brother and my sister shouldn't be able to have kids because he wouldn't want to

have anymore like me because I'm a threat to society. And we're spending taxpayers' money and he's paying for doctors and things for people like me. And if there were no people like me then, you know. That was kind of the worst thing especially because it was from family.

-Christa, 17 years-

Although Virginia did not personally experience any discrimination from her immediate family, she recounts the offensive remarks her brother (who also had albinism) and her mother had endured from their relatives. Being an African-American, Virginia's mother had been wrongfully accused of "sleeping with a white man". Virginia's account describes one of the many misconceptions people have of African-American people with albinism. In this case, relatives did understand albinism.

I haven't detected any difference in the reactions of my relatives, maybe because I had a predecessor. He was my brother, Ronald. He took all the heat and flack for me. When he was born my mother was accused of sleeping with a white man. My family on my father's side would not speak to her for a time. Some of them had to have known what an albino was, since I hear there is a lot of us in the southern states. Still, people see us from across the street and cook up their own ideas about who we are and where we came from. When my mother gave birth to two of us, there must have been some re-thinking. I heard that some of the older people would have nothing to do with my brother, at least at first. My mother tells me that one particular hard nose was determined that she would never warm up to such a freakish baby...Ronald died at the age of seven. He was killed in a fire. He was four years older than I was. Some of the things I do, I do for him.

-Virginia, 45 years-

It is evident then that the respondent's parents were extremely accepting and encouraging of their children's condition, and showed endless support towards their child. According to Martin (1986), nurturing parents who are responsive to the stigmatised child's social-identity needs can make a significant difference in the self-concept the child eventually develops.

Family was a safe haven, but the respondents would soon learn that the world beyond their homes was not as accepting of their albinism.

CHILDHOOD VICTIMIZATION: “Whitey, Casper, Ghost, Powder”

As my respondents stepped outside their sheltered homes, they were quick to discover that school was no refuge against maltreatment. All the respondents were enrolled in mainstream schools. Eight of the twelve respondents recall their childhood years fraught with taunting remarks from other children as well as some schoolteachers. Most of them were teased and endured name-calling as well as physical forms of victimisation. Class assignments and following the teachers’ instructions was especially difficult for them, due to their low-vision and inability to view the blackboard. Being physically different often caused loneliness and detachment from other class members. Most of the respondents recall their early school years to be unhappy ones.

Name-calling

“I remember more unhappy times than happy times”, explains Matthew. The derision expressed indicates that discrimination toward people with albinism starts at an early age. Many of the respondents related the times when they were the targets for name-calling and teasing. “Whitey”, “Powder”, “Ghost” and “Casper” are just a few of the derogatory names that children called them. They were also teased for having to use large print texts and having to move up close to the blackboard to read.

It was really kind of difficult because I was a very insecure person, then...When I was in elementary school I was the only one with albinism...In elementary school they'd look at me funny and they'd call me names like “Powder” or “Ghost” or they'd be like, “what

are you going to do for Halloween? You don't have to do anything. You can just go as yourself and everyone will think you're a ghost."

-Christa, 17 years-

Sometimes boys would laugh at me and call me "snow white"...One day, my brother's friend started to laugh at me because of my nystagmus, the fact that my eyes move all the time.

-Louise, 49 years-

When I went to school I found out that I had a difficult time because when the teacher would teach in kindergarten, I couldn't see what they were doing. But everybody else could and I was amazed what other people could see because they could see things. I had to ask people and they would say "can't you see that?" and I would say "no". So I really began to understand, when I went to school, what I couldn't do. Kids made fun of me. They decided that I should be the butt end of their jokes...As a child I remember more unhappy times than happy times.

-Tommy, 51 years-

I definitely remember it as not a pleasant time. Elementary school kids are harsh. That was probably one of the tougher portions of my life. I found it very hard mingling and right off the bat, people pick out you're different. I did have trouble with friends. I got a lot of teasing... based on my visual impairment.

Oh, I just remembered another guy. Oh, horrible. He was famous for picking on anybody because he was the shortest kid in the school and basically, if he didn't pick on people, he'd be picked on himself. I remember he was classic for starting the famous "whitey" thing and all the classic lines. So, the teasing was a big part of my younger years.

-Chris, 18 years-

Physical violence

In worse cases, the respondents were physically victimised by their classmates. Objects were thrown at them and they were spat at, ganged up on, and punched, on many occasions. As Virginia vividly recalls, children would "...throw things at me, hit me, stick me with pins...and kick me." These acts of degradation and humiliation often led to feelings of anger and frustration. Respondents did not feel a sense of belonging, and frequently wondered why they even went to school.

Elementary school was really bad. I remember when I thought I had a group of friends and all of a sudden they turned against me and they were doing things like spitting orange peels at me and I had a hockey puck thrown at my head. I had really bad things like that and people teasing me and joking and I just felt like "what's this class for? Tease Christa?"

-Christa, 17 years-

As a child I moved around a lot because my father is a musician and had to go on tour a lot. I went with him and my mum, so I therefore had to change schools regularly. I think this effected the amount of discrimination I experienced, as I couldn't form friendships and keep them like other children. It often takes kids a while to accept people who have differences, so as I moved on often they never had the chance to really get to know me. In primary school...I wasn't teased too much. It was when I reached high school that it became hard to deal with. In year 7, I was ganged up on and beaten up by whole classes of kids at once.

-Kim, 30 years-

I remember once when I was in Beavers, which is a younger version of Scouts, the whole time I'd been wearing a hat, which wasn't to cover up anything embarrassing...it was part of my uniform. And one kid knocked off my hat and people were really shocked when they saw me and they started to laugh and everything. My memory of it is very vague, but I don't think it felt good. I wasn't happy in elementary school. I only realize that now. Most people have great memories in elementary school. I'm usually happier at the present time. It seems to me that things get better. There have been a couple of times, but most of the time I never look back and say "those were better times than now". I didn't have a lot of friends back then and I had lower self-esteem.

-Matthew, 19 years-

Teachers as offenders

While the young children's cruelty towards each other is apparent, it is important to point out teachers' insensitive and often taunting actions and remarks as well. Many of the respondents recall the lack of patience that teachers displayed especially when the respondents had difficulty viewing the blackboard. "When I told them I could not see the blackboard, they would roll their eyes", Virginia explains. Evidently, teachers were indifferent to the obstacles the respondents were experiencing. Respondents pointed out, with outrage, that teachers showed a lack of support when they were openly

victimised by their classmates. Teachers were simply negligent and “couldn’t be bothered”.

Many of the respondents expressed their frustration, as teachers were insensitive to their needs. Respondents claimed that they were capable of doing the same assignments as the other children, however, they needed extra time to read the material due to their visual impairment. Yet, teachers showed no support. As Amy explains, “teachers thought that because I had a condition, I needed extra help on assignments...I could do it perfectly fine but the teachers figured ‘if she has a condition like that she must be dumb too’”.

Teachers...were also offenders. For example, in ceramics class the kids would break things that I had made under the tables, they would smash to the floor and the teacher would see this and turn his back and pretend like nothing was happening. This occurred lots of times. Once when I was beaten up by a whole class of kids I hit back one kid once and we were dragged into the office of the headmaster and I was blamed because I hit back, not actually making contact with the girl at all. Mum took me out of the school after that.

The teachers were totally unsupportive. I was pushed down stairs, ran away from by the children I thought were my friends, victimised by my teachers for not doing homework when I was depressed and couldn't keep up with other kids in reading the prescribed text books in English, because I read slow. In year 7, I would often pretend I was sick so mum could pick me up from school and I could get out of the victimisation. I would often come home with bruises crying. My parents felt helpless and ended up taking me out of the school because the teachers and principal wouldn't do anything to prevent it.

In 3rd class I couldn't see the board to read it and the teacher made us do a maths sum. I was called upon to answer the question that was on the board, but I couldn't read it. I told her this and she called me a liar. I told her that my eyes were bad, which all the teachers knew, and she dragged me up to the front of the class and hit me with the meter ruler in front of everyone. I never forgot this and I am angry to this day about that incident. In general, I felt totally unsupported by the teachers. I never felt safe in school, never feeling like there was anyone in authority to turn to. I felt so alone, but I guess it gave me strength to deal with things in my life. It gave me a real passion to help people less fortunate. Maybe that is one reason I became a social worker. It gave me strength, I believe, to deal with hard times in life... I could put up with school all alone, I can put up

with other stresses in life without caving in. The old cliché, "What doesn't kill you makes you stronger" really rang true for me.

-Kim, 30 years-

Some of the teachers were understanding. Some were really, really nice, but others didn't bother and said "I'm not going to do anything different for you because I can't be bothered." They understood that I couldn't see the blackboard from the back of the classroom, but most of them didn't understand that I couldn't go outside or else I'd get burned. The kids also always wondered why I had these huge math books with enlarged text.

-Christa, 17 years-

Teachers wanted to have as little to do with me as possible... I was never able to get on the honour roll like most kids because I couldn't do the work well. I became very auditory. I'm an auditory learner, a hands-on learner. I must do it to get it. I couldn't be a visual learner for most things, because if I sat in the front of the class, that wasn't close enough. So I had to move either up further than the front row, closer to the board, and I had to learn that when I was trying to get up to the board to see things, I would go to the left side to read the left side, and go the right side to read the right side. And of course, sometimes I'd forget what I'd read on the left side, so I would have to go back. And kids would always say "you're in the way, come on, I can't do my work!". Those things kind of hindered my work and made me feel bad.

-Tommy, 51 years-

Teachers did not want to be bothered with a visually impaired child. When I told them I could not see the blackboard they would roll their eyes. They would tell me to hurry up if I was copying something down. Some of them would consistently write everything down on the board in cursive and tell us to "copy that". I had to sit throughout the entire class while everyone else was busy writing. They would even write tests on the board. I was no, for the most part, given large print text to read, nor do I remember any attention to my special needs throughout most of school. The kids found that they could get away with anything in the classroom and the teacher would ignore it. They would throw things at me, hit me, stick me with pins, call me names and kick me, and the teachers would just look the other way. When I asked them to control the kids, some of them would tell me to sit down. One science teacher would bring in slide shows, the ones that had text at the bottom of the screen. He asked everyone to take turns reading. I couldn't read the print so I went to him one day and told him about my situation. He said I did not have to read. Then when class started he called on me to read anyway. I had to tell him again and again that I couldn't read the text but he called on me over and over. The kids were laughing. The other children thought I was very stupid and thought I could not read. What they didn't know was I used to go home and stick my nose in a book. I could read better than many of them.

-Virginia, 45 years-

Taunting bus rides

School buses were locales where frequent teasing and taunting occurred. Children took this opportunity to jeer at the respondents' physical differences. To make matters worse, all the children on the bus would join into the mockery making the respondent feel shamefully displaced, unpopular and isolated.

If one child wanted to be popular, he or she would make up a song or joke about me and the other kids would join in on the fun. Sometimes they would all break out into a raucous chorus of "Casper The Friendly Ghost" when I got on the bus.

-Virginia, 45 years-

School busses were always bad when I was at school and younger, kids could tease you and no one could stop them.

When I was younger I was teased on the bus, and once in the last year a young girl hassled me and my friend who also has albinism, saying "Yuck! Why would you dye your hair that awful color!" I just laughed at her and said, "for the same reason you dyed your hair that awful color!" She was young, on drugs it looked, and obviously very insecure.

-Kim, 30 years-

Isolation

Not surprisingly, the respondents who recounted experiences of school hostility were likely to indicate that they were neglected and isolated. Making friends was not easy and they often found themselves alone and out caste from the rest of their classmates. Being deserted was especially prominent during physical education, when their visual impairment made it difficult to focus on the object at play. Amy recounts, "I wasn't allowed to play certain sports such as badminton because I couldn't see the birdy". Physical education teachers were singled out as being particularly malicious toward children with albinism. With sadistic remarks from both teachers and classmates, the

informants were forlorn. Bergess clearly recalls these times of rejection, “who wanted me for their team?”

Often it was hard, very hard, the teasing and jokes and whispers. Little kids would point and ask their mom or dad who or what I was. After a while I would learn to ignore these, or a least pretend not to hear. I find it funny that a number of people have no idea of my heritage at all. Many think that I am white, although I am African-American. On some levels it allows me to walk in many circles...strange, but I can be noticed and sometimes not noticed. I get to hear what white people really think of black people...it's not a pretty sight, by the way. With it comes a low vision that really causes most of the problems as well as a lack of eye to hand co-ordination. So, I was never the best in sports. For guys, that can be difficult especially in baseball and football: two things you play on the street when kids. Who wanted me for their team?

-Bergess, 43 years-

I was not popular in the school playground. There were very few people who would play with me. I would stand and watch sometimes. When I had to play for gym I could not follow the softball. The gym teachers had the same impatience with me as the classroom teachers. They would make snide remarks to me when I missed the ball or took too long to get something done. They would say I wasn't paying attention.

-Virginia, 45 years

My first experiences started before I went to school. I noticed that all the children looked different than I did. I grew up in an African-American community so I didn't meet too many people who were light skinned. But I saw people at different times, so my first reality was to come back and ask my parents if I was adopted. This was before I was five, because I saw that everybody else was darker and I was so light and my parents were darker than I was, so I didn't know what was going on with that. I didn't understand that. I had blond hair, and I couldn't figure that out. They say “blondes have more fun, be a blond and see” and I'm up here saying “why am I the only blond? And I'm not having fun”. So, then I had ideas of what was happening...I thought that maybe my drinking white milk was helping to keep me white, so I wanted to drink chocolate milk because I thought chocolate milk would make me darker.

-Tommy, 51 years-

Between classes was another hard time. What made it really bad was when I had absolutely no support from the teachers. They ignored the victimisation making me feel more alone. My parents tried to be supportive but couldn't do anything in practice really because if they approached the principal like they had in the past, then I would be seen as a “dobber”; someone who told on people, and thus more unpopular.

-Kim, 30 years-

Discrimination was...a part of having albinism. I, of course, had less friends in school because I looked different. I wasn't allowed to play certain sports such as badminton because I couldn't see the birdie.

-Amy, 21 years-

These examples vividly illustrate the childhood ostracization the respondents endured. The prominent themes of victimisation that arose from school's hostile environment were name-calling, physical violence, offending teachers and taunting bus rides. Despite every child's wish to feel a sense of belonging with their class-mates, acceptance is a daily battle for children with albinism. Kuusisto, blind from birth, notes that "the craving to appear like your peers is an enslavement at any age, but is particularly bad at childhood" (1999:41). The results from the hostility the informants endured were, ultimately, feelings of isolation and loneliness. This made it difficult for them to develop feelings of self-worth as the self can never be formed in isolation, but rather is always embedded in the social context (Breytspraak, 1984: 100).

The only 4 respondents to report acceptance from their classmates and teachers in elementary school were Chantal, Julie, Louise and Tyrone. They reported that students as well as teachers accepted them as a member of the class and did not feel discriminated by others.

I do not believe that I experienced any degree of discrimination due to my albinism. I felt accepted by my peers and participated fully in the sorts of things that kids do when they are young. I took dance classes, art classes, swimming lessons, played in the school band, and completed Brownies and Guides. I played with the kids in my neighbourhood, and had friends at school. I was usually somewhere in the middle in terms of popularity.

Other kids sometimes asked, "why is your hair so white", but "it just grows that way" has generally been a sufficient answer. Mostly, the lack of pigment wasn't an issue, the limited vision was. Kids would ask me if it was true that I was "half blind", or they would make comments about how close that I held things. I sometimes got ink on my face from holding things so close to read them. It wasn't such a big deal in elementary school.

-Julie, 25 years-

I went to regular school, not the Institute Nazareth et Louis-Braille. Teachers were very nice. Kids too. We would share games. My desk was placed near the teacher in order to make it easier for me to see what she was writing on the board. This was from grade one to five.

-Louise, 49 years-

Personally, I have never had any discrimination...In kindergarten I went to private school because my parents didn't know how I would function with my low-vision. After I did kindergarten the nuns, they were sisters, they said to my parents that "there's no telling with her. She functions totally normally", except all I did was sit closer. And if I couldn't read the blackboard, well, then I'd walk to the board and read. Then I went to elementary school. No discrimination there.

-Chantal, 44 years-

In second grade, the New York State Department of Commission of Blind and Visual Impairment, assigned me a teacher. I'll never forget his name. He was my vocational rehab teacher and he would bring this old, beat-up typewriter, and he had taught me how to text type in second and third grade. I really felt that they were extremely supportive. They never pushed me to do things I didn't want to do. They challenged me to do things that would expand my horizon. And they really helped me to explore the many possibilities in life. I always had very good teachers.

-Tyrone, 42 years-

ADOLESCENTS: "It's kinda cool"

Nine of the twelve respondents indicated that as they got older and moved on to High School they experienced less prejudice and discrimination related to having albinism. Teachers were more understanding of their visual difficulties and other children and teenagers were simply curious about their physical appearance and posed questions regarding their hair colour and eye colour. The respondents reported that they felt increasingly at ease during these school years, as students were increasingly understanding of their condition. As Christa pointed out, "A lot of people think it's kinda cool".

A lot of people think it's kinda cool. It's such a nice contrast from when I was younger where people would make fun of me. Now my friends find it cool that my skin is so white and my hair is so blond. High school is really good actually. My friends all understand. I have a wide group of friends...I'm fairly dark for having Albinism, well, my hair. But I still get remarks like "your hair is so white and your skin is so white". But I'm still a little bit darker than most people with Albinism.

-Christa, 17 years-

I felt slightly more comfortable in high school...My more senior years in High School went pretty well. That's when I found my clique of people. People really got over their prejudice. It was pretty easy at that point. Grade 9, grade 10, grade 11 was my easiest year obviously. It was much easier to fit in at that point and I was much more accepting. So my last years were much better. Grade 9 was the year where things kinda switched over. I think the change was partly maturity, partly getting used to me being there. And well, you've got to deal with it after a while. The two mixed together...I mean, people are getting over it. They have their own things going on and they don't have time to go around picking on you.

For the past couple of years, things have been much quieter. People don't ask many questions. It's been a while since I've been tapped on the shoulder and asked some crazy question.

I remember being asked a lot of questions on the "red-eye" thing in elementary school and the early years of high school. I don't remember being asked in the later years...Some of the questions were on the general condition. Some of them were generally out of pure interest. Some of them are just naïve. There are different categories and you'd respond depending on the caliber of the question. A lot of the times I didn't answer. And part of me kicks me for doing that because I regret it in some cases because some people were just being sincere. But I guess at that point, I just didn't care. Honestly, now if I get asked a question, I'd be glad to answer it or often, I'd let one of my friends answer it...About two weeks ago, I was with a couple of friends of mine. One of my friends brought their boyfriend along and I could tell he was looking at me. The weird look. And so finally he says something... I knew he was going to say something to me eventually. So he finally asked me, "so, how much bleach do you use to get your hair that color?" And so my friend Nadia, who was standing right next to me just gave him this look. I'm like "no, no, don't give him the look, explain it to him." And so, I'll let them explain it at times. I mean, they know me well enough to do it for me. So often I won't have to answer them. People will do it.

-Chris, 18 years-

In junior high, I was very popular. I was in many many clubs and organisations. In senior high, I ran track, did cross-country. I was in dozens, literally dozens of organisations, and again, moved between the different social groups at school and never really had too much of a bad experiences on the school side.

-Tyrone, 42 years-

Teachers as supporters

Teachers were, for the most part, extensively sympathetic and supportive of adolescents with albinism. From making class notes available for the respondents, to elaborating on class discussions, teachers were more accommodating to the informants' needs. Thus making the process and experience of schooling more enjoyable.

In secondary school, I still had help when things were written on the board. I remember girls copying down the math problems that the teacher had given us, twice. They gave me one copy without me even asking them to do so. Otherwise, I would get close to the board after class or write the problems on a sheet of paper sometime during break. But this was a minor problem. A chemistry teacher, told me that the year I was in her class, she had a tendency to talk more than she used to in previous years. She thought that it would be easier for me than copying all the explanations written on the board.

-Louise, 47 years-

Teachers were not understanding of my visual impairment, not until later on...When I got to high school, my biology teacher was the first teacher that let me see his notes and copy them. That really helped out a lot because I couldn't read them from the board.

-Tommy, 51 years-

Curiosity and questions

As the respondents and their classmates matured and entered High School, they experienced fewer derogatory remarks. As Chris explains, "...people really got over their prejudice [and] it was pretty easy at that point... I was much more accepting." In their childhood years, the respondents endured teasing and victimization mainly because of other student's fear of their condition. However, in High School, fear turned into curiosity and teasing was replaced by questioning. The respondents were frequently posed with genuine questions of curiosity. The most common concerned their visual acuity, hair color, eye color and skin color.

Now that I'm older I find it easier, but I still find myself explaining all the time. Now they don't tease as much but they ask more questions about my condition, like "why is this like this?". They ask questions both about my appearance as well as my visual impairment. Once I had some difficulty with my balance and I had to use a walker for two years and everybody thought it was because I was blind since I also wore sunglasses. I had to explain that, "No, it isn't because I'm blind", and I had to explain what my vision was.

-Christa, 17 years-

The only thing that was different for me was that I had to learn to deal with people to a much greater degree than most kids. People would stop me on the street or in a mall to tell me that I was beautiful. They would want to touch my hair. They would ask me if I had albinism, or if I was of Nordic descent. They would ask what my parents looked like. They would ask why, if I had albinism, didn't I have red eyes. They would mistake me for another person they know with albinism, or ask me if I knew their friend with albinism. At first this made me feel uncomfortable. It was difficult to just accept compliments, and talk openly with people. Eventually though, it helped teach me to be polite, and friendly.

This kid from another school used to see me around sometimes and yell "hey snow white" when he saw me. I usually ignored him, but once, when I saw him at the candy store, I got sufficiently annoyed that I finally told him it was better to be snow white than a dwarf (he was shorter than me). After that, he still said, "hey snow white" whenever he saw me, but he said it different. More like it was a friendly nickname. Really, I think he was just curious about me, but didn't know what to do about it. From then on, he always called me Snow White and expected me to respond with, "hey, dwarf".

-Julie, 25 years-

I worked with children over the summer. I spent my summer travelling and working with children. They were much more open about it and about asking questions. They'd ask me "why do you have white white hair?"

I don't have problems with people asking me questions. There was one kid who was rude, but very vaguely. I said that I was born with this way and he had no problem after that...actually even around Vanier, some people really don't mind asking. They ask about my hair color. They also ask how well I can see, but that involves knowing me a little bit better.

-Matthew, 19 years-

Respondents expressed that early school years were especially trying. However, due to the increased knowledge and understanding that teenagers have of people with physical differences in general, making friends and "fitting in" was made easier for the

respondents during High School years. When contrasted to the childhood years, three main themes were depicted from the respondents experiences as adolescents: acceptance rather than isolation; teachers as supporters rather than offenders; and being posed questions regarding albinism rather than being scorned because of it.

The respondents recounted that many classmates posed questions about albinism, out of curiosity. Many were fascinated by their appearance and found it “cool”. Others asked about their visual impairment and whether they were born with low-vision. Those, however, who were still not comfortable in approaching the respondents would simply give them “the weird look”.

Although there was still the occasional remark that was directed towards having albinism, High School years were considerably more pleasant than childhood years. From teachers to students, the informants were being acknowledged increasingly for their talents and personal qualities, rather than merely their physical characteristics.

ROMANTIC RELATIONSHIPS: “Orange in a world of apples”

Dating was difficult during the teenage years, most of the respondents reported; but such difficulties seem to ease up later in life. Among the older members of the sample who were 30 years and older, three were single, two were married, and two were divorced. We discussed how albinism had affected romance at some length, and their experiences and insights varied quite considerably.

Some people experienced derision, others found that the inability to drive more problematic, some found the initial meetings a trial, while others are more solitary anyway. One man “had a lot of no’s”, another said that he was “seen as a case”. A girl complained that because of her poor vision, “I don’t notice guys checking me out!”

Different people hold different problems. Julie cheerfully put it, “I feel like an orange in a world of apples.”

“Fascinated by my albinism, and not me”

Dating has not been easy. I'm not going to blame that right away on albinism because I'm a very fussy person by nature...But I don't think of it as a positive factor, let's put it that way. I won't jump to the conclusion to say that it's a negative one.

One of the attitudes I get which really irritates me like you would not believe is “it's so cute”, but like a puppy kind of cute, which is really irritating. It's like “your hair is so nice” but it's not looking at the person. If I were to use Leonardo DiCaprio, god forbid, they'd say, “his hair is beautiful”, but they're looking at him. They see a person. In my case, they're seeing this totally weird – to them it's weird. And so they see the hair, “cool hair”, but it's nothing further than that. In that respect, I get looked at differently, which is unfortunate because you don't have the opportunity to be seen as a person. You're seen as “this case”. It's not the same. So, I am looked at differently which is annoying.

I did at one point go out with someone with albinism so that was like a non-issue at that point. I had one girlfriend that was very intrigued by it. She was fascinated by it. That was a short-lived thing. It didn't have any basis...in general, she was fascinated by it in a way, and not me.

-Chris, 18 years-

I was talking to my friend and telling him “Well, I don't know, I just don't know what I have to offer”. And he was saying, “Well, you know, you'll be fine.” I think that maybe he thinks that I might scare people a little in the beginning, but when they get to know me, it'll be different.

-Matthew, 19 years-

Adult respondents also shared their dating experiences. Tyrone, recalls his teenage years and explains how dating, in High School, was a tremendous “challenge” because of the pressure placed by schoolmates.

In high school, dating was a little bit more of a challenge...In high school, I think it's a challenge for most kids. Even someone who's well adjusted is going to have a challenge in high school because it's so peer driven. Whereas in college, people see you for more the individual that you are, and so it really was not a problem.

-Tyrone, 42 years-

“Striking appearance”: Parties and Dances

School dances and parties were venues where the respondents were singled out because of their albinism. Respondents were often the center of derision and mockery. Even when they were invited to dance, they were skeptical as to whether they were asked out of pity or genuineness. The participants explained that their appearance was of most concern. During times when they were rejected or alone, they instinctively knew it was related to being a person with albinism.

Dating was hard...you're always looking for a boyfriend. When all your friends have a boyfriend you want a boyfriend because you want to be like everyone else. Now, it was like that to a point and then I met my husband, I was age 16. So, I didn't really go through that very long. When I was 14, my friends started to have boyfriends and I didn't have any. We were a group, a few friends together, and we were boys and girls. But then some girls started to have a boyfriend...we would still go out as a gang...we used to go to school dances. That was...popular at the time. We didn't go to discos and so we went to school dances. Now, you'd be standing there waiting for a guy to ask you to dance, but then some wouldn't and some would. So, you had...good nights and you had bad nights. But probably, all the girls went through that...where they had good nights and they had bad nights. But when you really look different, sometimes I would wonder "is this guy dancing with me because he has pity on me because he saw me there alone while my girlfriends were dancing with other guys?" But, you don't know...but you know it's just flashes. Like, for me, I wasn't possessed by that. But there were times when I was sad because I'd question if it's because of that [having Albinism]...you don't even have to question if it's because of that. You know it's because of that.

-Chantal, 44 years-

I'm not married nor am I in a romantic relationship but I'm sure it's got nothing to do with my condition. My solitary personality is the reason why.

Being a teenager was a more worrying time for me. Appearance at that age is so important. We dream of prince charming and we want to go out to parties. I was not the most popular girl for the boys. I was far from that. But as the years passed and at around the age of 19...I met friends who introduced me to others. Although the look is still important, maturity changes ones objectives.

-Louise, 49 years-

In high school I was always put into the position not to hurt or offend. All I could do was be aggressive enough to ask, and they would tell me "no". I had a lot...of "no's". I

remember a lot of guys would say, "oh, man, every girl I ask, all of them didn't say yes either" but that wasn't what I was saying because I was seeing that all the girls that I liked, liked somebody else and they had no time for me...

Females discriminate probably more so than males. Females, black, white, or whatever, tend to have a persona of what they want their lover, their husband, their boyfriend to look like, to be. Certain attributes everyone wants. Most of the attributes that they really want are more visual as opposed to being emotional and mental. And so, therefore, they go for the physical things. I mean, that's what we pick on. We look at visual. You see somebody you are sexually attracted to, and it becomes that kind of draw...Somebody sees you and they say it was love at first sight. Well, I've never met anybody who has said to me, "I've loved you the minute I laid eyes on you."

-Bergess, 43 years-

The difficult dating experiences expressed by the respondents indicate that people with albinism are often rejected during the High School dating years. Despite their peers' comments on their "cool" appearance, the respondents explained that their physical appearance was a main factor that caused their unpopularity amongst their peers in relation to dating. Many respondents explained that their peers were not interested in building an intimate relationship with them. As Chris explains, "...they see the hair, "cool hair", but it's nothing further than that...you don't have opportunity to be seen as a person. You're seen as 'this case'".

Ten of the twelve participants expressed their belief that their physical appearance was the reason why others were not intimately attracted to them. A few respondents recalled times when their peers openly made derogatory remarks but, most times, the participants were plainly ignored and avoided. The respondents explained that, internally, they knew they were rejected because of their condition. As Chantal painfully recalls, "...there were times when I was sad because I'd question if it's because of that [having albinism]...you don't even have to question if it's because of that. You know it's

because of that.” The respondents’ low vision also had an impact on their dating experiences as it presented certain inconveniences, in particular, the inability to drive.

“Can’t drive because of my vision”

Along with their “striking appearance”, the respondents’ visual disability affected their ability to form intimate relationships. Most of the respondents claimed that their incapability to drive caused many inconveniences for their partners and themselves, especially when it came to dating.

I'm married and I have kids. However, dating was a disaster! First of all, I didn't drive. I can't drive because of my vision. And there are a lot of women who didn't want to be with anybody who couldn't drive. Then the second thing is the way you look, my striking appearance. They would make fun at me at parties. They would say, "let's cut the lights out and see who glows" and then when you're dating, the person who you would like to consider has to also be brought into the teasing. You know, "you like him, but you'd better not kiss him because you might start looking like him"...I was an only child. I had never seen another albino until I was about twelve years old. So, girlfriends were basically hard to come by because some girls just didn't want to be teased along with me. Therefore, they would rather stay away, even though, I might have been a nice looking guy. It's funny, girls only wanted to go out with who the girl group approved.

-Tommy, 51 years-

I was married for 20 years and just finalizing a divorce. Being an albino didn't hurt or help the relationship. Maybe hurt a little. Cultural differences may have played an impact but being an albino was really secondary. My vision played a role in activities...so that had an impact. We had to work around it. Being single again I think about the dating situation a lot. It can be hard to meet people romantically until they get to know me.

-Bergess, 43 years-

I did not really date through junior high and high school. Aside from kissing games in junior high, and one long distance boyfriend in high school, it was not until university that I actually dated to any real extent. Albinism affects my interaction with the opposite sex in two ways. First, guys notice me a lot because I stand out - I have platinum blonde hair nearly to my waist, I am 5'7 and weigh 105 pounds. Second, my vision is sufficiently bad that I don't notice guys checking me out. I am sure that I would have dated more if I could see better to recognise people, and their reactions to me. I am not able to see

someone looking at me, and then smile back at them, for example. Also, if I have only met a guy once or twice, I probably won't recognise him the next time that I see him. Looking different didn't make me feel unattractive, but it made me somewhat unsure of myself. For lack of a better analogy, I felt like I was a pretty okay-looking orange in a world of apples. I felt that I looked good, but so different that I was incomparable to other people. Kind of like a cartoon character superimposed onto live action video. When I first started going out to bars with friends I went a bit nuts.

One summer in particular, I went out a lot and it was a slow night if I only met one guy. The guys were generally good-looking, a couple of years older than me, and obviously the sort of guys that went to the bar on a trophy hunt. I totally ate the attention up too. I never had issues with self-confidence, but being hit on like that made me feel attractive by regular standards instead of just being different looking. Again, I do not really notice people reacting to me, but other people do and tell me about it. Scott, one of the guys that I know here at the university, once asked me if I see the way the men look at me. The last time that I went out with all of my roommates me and Melissa were walking back to our table and she said all the guys we walked past in the bar went nuts. Again though, I can't tell. Admittedly, if I could see well enough to tell I might feel different about it. Dave, the guy I am dating right now, and Scott both do this and it bothers me. If I say something to them like, "oh that person at the ticket counter was really nice to me", or "the box boy at the grocery store was really friendly", they will dismiss it as people only being nice because I am very blonde and wearing a short skirt. Not that people aren't genuinely nice and friendly to me because I am an outgoing and friendly person.

I have asked boyfriends how they feel about my albinism, and they don't have a problem with it. Usually they are just interested to know more about it, and think that I look attractive. Again, the issues for me are not with pigmentation, but with vision. All of the guys that I have dated except one were fully sighted. Sometimes guys don't understand my disability. The guy I'm dating now was going to let me take the wheel of his brand new \$30,000 car couple of weeks ago when we were driving on the highway and he was putting film in my camera. The guy that I dated before him understood my vision, but felt that it made me slower at doing things, and he sometimes got frustrated when I couldn't see stuff. He said that going to the Disney Animal Park with me was less fun for him because he was so worried about me not being able to see the animals. If I dated another partially sighted person, these things wouldn't be problems.

-Julie, 25 years-

The only issue now for [my fiancé] is that I can't drive. He finds this difficult to deal with but understands. There is a possibility I may be eligible for a license, which he is excited about, but he does accept it none the less.

-Kim, 30 years-

From these examples, it is evident that when discussing their past or present relationships, the respondents explained that any problems or difficulties that did arise in these relationships due to albinism, were related to visual impairment. However, those who were dating or married at the time of the interviews, indicated that their partners were very understanding of their visual impairment despite the occasional inconvenience, of not being able to drive.

“Likes me for who I am and not my condition”

Most of the respondents reported that they dated more frequently after High School. The adult respondents, who are presently in close relationships, explained that their partners are attracted to their personality and other personal qualities. Unlike their High School dating years, they are not judged on their appearance or visual impairment. The respondents expressed feelings of content and confidence as their partners acknowledge and praise their numerous positive attributes and capabilities instead of emphasizing their limitations.

Well, during school I never really went out with anyone. The boys either made fun of me or ignored me. As I got older, I had crushes on guys and I finally found a guy that likes me for who I am and not what my condition is. I have been seeing him for over three years now. He is the best. I plan on marrying him. He knows about my condition. I feel comfortable around him and he raised my self-esteem like nothing else. As I got older I had a much better time discussing my condition with others. Before I would just look away or ignore any questions.

-Amy, 21 years-

I am engaged to be married at the moment and will be married in November. I have found in the past though that I didn't date as much at school and soon after. I put it down to my albinism and looking different, but I can't prove that and it may just be my paranoia or an internalized inferiority complex. Whenever I went on blind dates...I would always feel a little uneasy, in the back of my mind, thinking that when they find out that I look a little different that they won't want to continue seeing me. I would usually

tell them beforehand on the phone that I was very very fair, to warn them. I didn't seem to have problems dating in these situations. Some that I dated wanted to see me again and others didn't. I guess that I didn't get an overrepresentation of rejections as compared to the general populations.

At school, on the other hand, dating was non-existent! As I was victimized a lot, I was not the one to date there. If people dated me then it wouldn't look too cool for them. I was always "friends" with guys at school, but never romantically involved. When John came along, my fiancé, he didn't seem to mind. It was a blind date also. We met on a phone dating line and spoke on the phone for about 2 weeks before finally meeting. I hadn't told him I had albinism. Maybe I felt a little self conscious, as if he may prejudice me based on stereotypes in the media and film, and I certainly don't look like anything you see in the movies! So I told him I was fair and he worked it out for himself later. He thought I was pretty and we fell in love. I did ask him however, would he have continued to the point of meeting me if he knew straight away that I had albinism. He honestly said that he thought that he may not have continued with meeting me for the first time... but after he saw me he liked what he saw and who I was... and here we are getting married!

-Kim, 30 years-

I really care for someone now who likes me for 'me' and that is really special to me.

-Bergess, 43 years-

I've been married 25 years and I have 3 three daughters that are ages 20, 22 and 24. The three girls carry the gene but they do not have Albinism. When I met my husband... I think he looked more at the person, the inside, rather than the outside. And...I was a good looking girl. I was tall and slim and I was always told that I had a very nice personality and that I'm very very sociable and I'm easy to talk to. I met my husband through another person that I knew and he just introduced me like that... my husband had just bought a new car and he said "did you see Norm's new car?" My husband's name is Norman. And I said "no". I didn't care about cars. I was 16, my husband was 21...four and a half years apart...So, that may be little different too. Maybe a 17-year-old guy wouldn't have looked at a woman the same way as he did. Actually, he was looking for someone who was smart... that's what he told me at the time. He's an honest person. But he never referred to the albinism and I would be the one who would say "hey, I don't see this" or "tell me what you see because it's too far, I can't see it". I function very very normally, and even my husband would say that sometimes he forgets that I can't see...even my daughters too. They forget that I can't see.

-Chantal, 44 years-

It would appear then, that during the High School years, the physical appearance of people with albinism is the main factor that hinders the formation of

intimate relationships. During the later years after High School, respondents reported that they dated more frequently. Those participants who were dating and married at the time, indicated that the main cause for dissolution of previous relationships was due to their visual impairment. The most commonly stated inconvenience caused by the low-vision was the inability to drive. Furthermore, all the adult respondents who were in intimate relationships at the time of the interview expressed that their partners were attracted to them because of their positive attributes and personality. These responses from adults were contrary to the teenage respondents who expressed that schoolmates were fascinated by their albinism rather than their personality or other internal qualities.

CONCLUDING REMARKS:

This chapter has focussed on illustrating the adversities that people with albinism face at different phases of a person's life, including childhood victimization and intimate relationships. On the most part, it was found that early childhood years were filled with unhappy memories of victimization from classmates and teachers alike. As the respondents reached High School, however, they experienced fewer discriminatory remarks and found it easier to form friendships.

Family dynamics was portrayed as a safe and supportive environment – the sole place where respondents were free of discrimination and victimization. Parents as well as siblings were very accepting of the respondents' condition and constantly were a source of praise and comfort.

Dating was difficult during the teenage years. Since people with albinism's physical characteristics are openly visible, their differences often affect others' impressions of him or her. The respondents' experiences indicate that the physical

appearance may be an obstacle in the primary stages of establishing an intimate relationship. During the adult years, however, respondents dated more frequently. Relationships that did not last were mainly due to the respondent's visual impairment.

So far, the respondents have chronicled in detail about three areas of their life in which people react to their condition. The next chapter will describe their reactions in other areas of their life: employment discrimination, the medical profession and in public.

CHAPTER 5

EMPLOYMENT, MEDICAL PROFESSION, AND PUBLIC TREATMENT

This chapter will focus on the respondents' experiences of treatment at the workplace, with the medical profession and among the general public. People with albinism are very visible, and strangers can react very strongly, and strangely, to them. This chapter will lead on to a discussion of how people cope with those whom Goffman called "the normals" and the new Disability theorists describe as "the problem".

EMPLOYMENT DISCRIMINATION: "See that short albino"

Having albinism is not a bonus in our appearance-oriented world, especially in the area of employment where one is often hired for one's image as much as one's skills. Therefore, it was not particularly surprising to hear that participants experienced various forms of discrimination during their employment. Discrimination, in this case, refers to both hiring bias and differential treatment.

More than half of the respondents reported having been discriminated against at the workplace because of their albinism. Emotions including frustration, aggravation, humiliation, hurt and degradation abounded when they shared their experiences of mistreatment. Both physical appearance as well as visual impairment were reasons for the prejudice they endured. Two of the participants claimed they were fired from their job due to their poor vision. One of the respondents was not hired because of her low vision, and four of the respondents reported having experienced humiliation, disrespect and avoidance by their colleagues. Both men and women experienced discrimination at the work place.

Discouraging employers

For people with albinism, seeking employment is especially difficult since both their appearance and visual impairment play a role in the manner in which employers regard them. Many of the respondents expressed feelings of frustration and hurt as employers continuously stressed their limitations while overlooking their abilities. In worst cases, respondents revealed that they dread the task of searching for employment as they fear being shunned and rejected again.

I was fired from a job because I couldn't see a TV monitor that was high up on the wall. I worked in a fast food place and employees were to read this TV screen to know what the next order is, but I had a hard time reading it. The employer didn't even give me a chance to try.

When I worked at the fast food place I thought I was doing such a great job but the employer would watch me like a hawk. At those sorts of places you need to be fast and learn the stuff fast but for me, it takes just a bit longer to read and get it right. The employer didn't have time to give me a chance so she fired me. After this experience I was afraid to apply anywhere else because I figured they would fire me too.

-Amy, 21-

I'll start by discussing the time when I was looking for a job. At the end of the year at commercial college, the director sent students to an employment office for fill out applications. When we arrived there, the girls who came with me didn't want to go in. They were shy and nervous. When they started walking away, I told myself "that's why I came here for" so I opened the door and went in. That's when I heard a girl say to her friends, "hey, she's going in". So they followed me. However, chances are that they got hired since I didn't impress the receptionist when I was filling in my application form. I was looking at my sheet very closely.

I'll always remember...when the manager told me, "Your sight is bad. You won't be able to do the job."

-Louise, 47 years-

When I was about sixteen, I worked at a place which had a horrible lady who would never let me do any important jobs that dealt with money...she thought it would be getting my hopes up about having a proper job because, as she saw it, I would never amount to anything. So why give me false hope?

-Kim, 30 years-

Disrespecting colleagues

Once people with albinism overcome the obstacles of being employed, they are often faced with having to cope with disrespecting colleagues. As the respondents recounted, they have experienced various accounts of degradation, humiliation and hurt by their colleagues. Respondents received rude and disdain comments. As well, they were often ignored or ridiculed.

Discrimination at the work place has always been with adults... Adults are very interesting. They are canning and they will say things like "Oh, how did you get here?" or "when did you get that?" or "how did you get that?" or "how did you turn out like that?" So I listen to their words and the questions and the way they phrase it and it's as if to say, "you don't deserve that" or "I've very happy for you that his happened to you". They don't say that. They want to know "what makes you think you deserve this" or "what did you do?" Basically, they're saying, "you shouldn't have that, this should not be happening to you." I used to be indignant. But now I'm more conciliatory in saying...I just try to be respectful. I mean, I've been hurt. I remember one time, with a new student. He said "Mr.Bryant", I said "yes". He said, "I'm your new student in your class". I said "ok." So then a minute later I kind of approached him and asked, "how did you know I was Mr. Bryant?" I was standing next to a white teacher who was a colleague next to me and he didn't stop him, and so I asked him, "how did you know I was Mr.Bryant?" And he said the assistant principal said, " go around the corner to see that short albino." And I'll never forget that because I wanted to go there and cuss her out. First of all, she disrespected me in front of a student and she made the student, which happened to be a good student, know who I am in that way. It really irritated me that it came from an adult and not a student, one of my professional colleagues! So, that showed the level of respect that they had for me.

-Tommy, 51 years-

I had a six-month contract with the Veteran Affairs and I was working in the Human Resources branch and I was the Director's secretary. And naturally, you know, the director, they need a lot of managers and all that. And there was this man, he was a doctor, because you know how veterans come and they need their medical so that they can get their pensions. And one day this doctor came to see the director and I was at my desk and I'm reading or doing something on the computer and he said to me, "isn't that awful. Don't you think you should change your glasses?" And the guy was a doctor, but he obviously didn't know I had albinism and that I have a visual impairment. And often people say that. Well, I haven't heard that in a long time now, but very often when you're reading, people would say, "why don't you wear glasses?" Because I take my glasses off to read but I wear my glasses to look at a distance. So, that's what people would say.

“Why don't you wear your glasses or why don't you change your prescription?” That's because I put the paper very close to my face when reading. I read the regular print, but I just read it very close...you develop mannerisms, where it's an automatic thing to throw everything in your face.

-Chantal, 44 years-

Once I had an interview scheduled for a job. When I walked into the front office all noise stopped. It was like one of those Twilight Zone episodes when water stops in mid-pour and people stop in mid-sneeze. I was met by two women who stared at me without blinking. I told them what I was there for and they looked at each other. I was escorted into the boss's office to wait for him. As soon as the office door was closed the two women burst out laughing. I met with the boss and when the interview was over I opened the door to leave the room. There was another woman sitting at a desk who had not been there before. As soon as she heard the door open she spun around to stare me right in the face. I did not get the job.

Another job I had was in a shipping department. I was told how friendly the people were and that anyone would help me if I had a question. Wrong. Some of the workers would not talk to me or answer my questions. When they saw me coming they would turn their backs and ignore me. I would hear the other workers laughing or making comments while I tried to get help. That job did not last long. I was let go for not doing my job. When the other workers found out they openly scowled at me.

-Virginia, 45 years-

These examples illustrate the vulnerability of people with albinism. They are often mistreated and given differential treatment because of their appearance and visual impairment. Many respondents felt that employers and colleagues were not understanding of their visual impairment. The participants were confident in being able to perform the tasks that were necessary. However, because of their low-vision they required more time. As Amy pointed out, “the employer didn't even give me a chance to try”.

The respondents, who did not report having experienced any blatant discrimination at the workplace did, however, receive subtle remarks concerning their visual impairment. A recurring theme was the impression that employers and colleagues

felt that the people with albinism's low-vision would effect their ability to perform their tasks.

I have never had trouble finding work. Through high school I taught children's art classes with the local recreation department, and one summer I worked with their Head Start program for kids starting grade primary in the fall. The recreational department did not take issue with my albinism, although I once taught a class with a woman who expressed concern about me not being able to safely monitor all the children due to my visual disability. I was a bit hurt by this, since it implied I could not do my job as well as other staff, but I can't say that I hold it against her. It is hard for people to understand what I see, and what I can or can't do. Besides, you can't blame someone for wanting to be careful when little kids are involved. When I worked with kids at the recreational department they often asked, "why is your hair so white?" Like I said though, "that's just the way that it grows" was usually a sufficient answer. Sometimes little girls would tell me that I was very pretty. Babies and small toddlers just stare.

I have had lots of other jobs, mostly working in an office environment. No one there ever said anything. Working as a teaching assistant here at the university was a big step for me though. It is the sort of job where it is obvious that I don't see well. Students often ask why I need to be so close to the computer screen, or if I need glasses. No one has ever asked about my hair or skin though. I get along extremely well with my students, and am glad that I finally got the confidence to work as a TA. In September I will be lecturing the first year computer science class. I am somewhat worried about how my eyesight will effect my teaching, but I am not worried about the way that I look. My disability has never been an issue for the computer science department here. They have never asked me if I can do things, or if I feel comfortable doing them, they just expect the same of me as the other grad students.

-Julie, 25 years-

At all my jobs I've had really supportive employers so there's never really been a problem. There's been comments passed by my fellow co-workers but I cleared the air right away. They made comments on my vision. I worked at a day-care facility for several years and on a couple of occasions there were comments passed on about my vision, and I clearly stated that it didn't interfere with my ability to do the job. And so that was set straight right off the bat.

-Chris, 18 years-

My speciality background is radiation therapy, so I treat cancer patients. However, I started working in 1981 immediately upon graduating from undergrad and I started teaching. So, I've been in higher education for almost twenty years now. I have done clinical work and as a clinician, sometimes you'd get a look or something from a patient. But by and large, in every job that I've worked in, I really can't say that I've experienced any overt racism or bias directly due to my albinism.

-Tyrone, 42 years-

I feel that I am totally respected as a professional and my albinism never comes into the picture. Sometimes patients in the psychiatric unit I work in ask me about my eyes moving or about dying my hair, they are often more up front than others in society, and I just tell them straight out what I have and why.

-Kim, 30 years-

It would appear then, from the experiences of the sample members, that their visual impairment is of most concern when being hired for a job or when performing the tasks required for a job position. Only in a few cases did respondents report that their physical appearance induced disrespectful behavior from others. Since people with albinism often bring reading materials close to their eyes when reading, people often make insensitive remarks. It may be more difficult for people with albinism to find a job where their visual impairment is not of great concern, and then to worsen the situation, it may also be hard to find a job where they are treated with respect.

MEDICAL PROFESSION: “Woefully and piteously ignorant.”

More than half of the sample reported feelings of exasperation about the medical profession’s ignorance about albinism, as well as the manner in which they were treated as a “new case”. Since albinism is a rare condition, doctors and nurses very seldom meet patients with albinism. The respondents reported that when the doctors received a patient with albinism, the doctors seized the opportunity to examine them. As Bergess pointed out, “I think that I was an experiment for the doctor and a highlight for her journal.” Virginia was more forceful: “The medical profession is woefully and piteously ignorant of us...I have come to hate the stupidity of the medical profession.” Kim agreed and recited a list of negative experiences. Tommy was furious: “All they want is money”. Chris reports how one optometrist was insulting and a doctor “who was actually scared of

touching me...and another was shaking. That's a classic." A few respondents explained that as soon as they were born, physicians told their parents that they would grow up to be "blind and retarded". What is particularly striking is how many and how frequently the doctors were simply wrong, and how much they have alienated their patients, the very people they are supposed to be helping.

The medical profession is woefully and piteously ignorant of us. Not only that, they are smug about what they don't know. In this day and age, they are still telling frightened parents that their precious children will be blind, deaf and have retardation. They are telling them that they are likely to be sickly, weak and die of some disease. One mother called me to say that a doctor told her and her husband that their daughter could never play any outside games. They were keeping the baby in the dark in the house. This was five years ago. Another doctor just last year told an expectant pair of parents that their baby would have albinism and in the same breath asked them if they wanted to keep it? I have come to hate the stupidity of the medical profession. Each time I am seen by a new doctor the same questions are asked and the same comments are made. They examine me and say how surprised they are that I am healthy. They ask me if I have any other family members who have albinism. When I tell them about Ronald they want to know how he is doing. When I tell them he is dead they say, "Ah ha, did he die of HPS?" I roll my eyes and heave a sigh and have to say "no." Once I went into a doctor's office. There were two of them. Usually when one sees me he or she goes and comes back with at least one other doctor. This particular one looked at me a long time and told me he was concerned about my health because of my pale skin. He said he thought I might be anaemic. I had to fight to keep from laughing. I told him I was not anaemic, that I was an albino. I sometimes use the word albino to people whom I think are none too bright and might not understand the long word al-bin-is-m. He kept checking my fingernails to see if I had streaks in them. This is supposed to be a sure sign of anaemia. I was wearing nail polish so he couldn't see anything. He took his partner outside and left me to sit there for a minute. Then they came back in and kept looking into my eyes. One of them asked the other, what he thought. The other kept saying, "Nope." I asked what they were saying, "nope" to. They told me that if I were an albino I would have pink eyes. I got sarcastic and said, "I would have white hair too." One bobbed his head up and down in triumph as if he had caught me at something and with a big grin on his face said, "Riiggghht."

-Virginia, 45 years-

When I was born mum looked at me and said, "Ohhh, she looks just like a little albino!", and the nurse said, "how dare you say that about your baby Mrs. Piense!" I wish I could see that midwife now! Sometimes doctors say to me, "do you know you have albinism?" and on the other side of the fence, one asked me when I told her I had albinism, "how do you know? Have you had tests?" I couldn't believe her ignorance! Eye doctors shine

eyes in my eyes sometimes without warning, which hurts like hell. When I was a little girl mum had a doctor tell her coldly that I was blind, that I'd never be anything and that she should put me in a special school and buy me a white cane. Another told her to give me up and put me in a home for retarded children. Others told mum and me sometimes also, that I didn't have albinism because my eyes weren't pink. I personally take every opportunity to educate doctors about my condition... if I can help one doctor understand albinism then it may help so many others in the future who have to deal with that doctor.

-Kim, 30 years-

The doctors used to always tell me "you can't see well and you can't do this or that". He'd tell me my limitations so much before I stopped going to him. He didn't have any hope for me, so you know, that's about it. They're brutally honest.

-Tommy, 51 years-

"An experiment for the doctor"

Many members of the medical profession seldom have patients with albinism due to the rarity of the condition. As my respondents explained their experiences, it was clear that once the respondent walked into the doctor's office, many of the doctors sought the advantage of treating the respondents as a new case for their research.

When I go into new places or the hospital I really get noticed...sometimes I get questions or someone will say something stupid like, "did you know you were an albino? Or did I know I have poor vision and did I know what caused it?" A couple of years ago I had a screening for skin cancer. I think that I was an experiment for the doctor and a highlight for her journal.

-Bergess, 43 years-

All they want is a patient. All they want is money. They don't care if you're black, blue, or purple. As an albino, it's no big deal. I mean, they don't know much about it. I know more about it than they do. I've learned that there's nothing medically different that I have than any other person who's normally pigmented, in terms of looking for something supernatural that was wonderful to have that anybody else didn't have.

-Tommy, 51 years-

While some members of the medical profession treated the respondents as "cases" or an "experiment", others were indefinably fearful of the respondents' condition. From the participants' experiences, it is apparent that doctors and nurses are not always

knowledgeable about albinism. This kind of reaction from members of the medical profession often elicited feelings of frustration and disbelief from my respondents.

We've gone through a couple of doctors where we've left because of some comment that the doctor passed...We went to one of these Lunettier places to have one of my pair of glasses fixed. My mother brought me in there and he [the optometrist] couldn't read the prescription for some reason and so she said "well, can you have it faxed over whenever you guys re-do it." And he said, "well, I'll put in whatever you want. It doesn't matter, he doesn't see anything anyway." This is the optometrist! And I'm sitting right there! Luckily my French wasn't that good at the time and I didn't understand what he said. But ever since, we haven't gone back there.

I remember one doctor who was actually scared of touching me. It was very bizarre. You could tell he was very hesitant. He didn't say anything but I could tell he was very nervous and very on edge. Oh! And there are my stitches! I forgot about that one. This was caused by a mixture of a visual impairment thing and stupidity. In our basement, we have half moon lights that come out of the wall. They're metal and they're sharp on the top and the bottom. I had walked under it and you know, I was growing up at that point, I guess, and so it didn't hit, but it sliced along. So I had this nice gash on my head which freaked me out by the way. So I had gone to this clinic to get something done to my head, and the doctor was just so nervous when he walked in. You could tell, he was breathing quickly. He had to numb my head with this little needle. He was so nervous he was shaking, he dropped the needle! And I have a fear of needles. You can do anything, but just don't show me the needle. And he dropped it right in my lap, and I was like "this is over now!" You could tell as he was passing it through, he was shaking. That's a classic example, now that I think about it. I've never even thought about it before.

-Chris, 18 years-

These quotes vividly illustrate the malicious and uncaring remarks and behaviour that some respondents endured from general practitioners and optometrists. The doctors discouraged respondents and emphasised their disabilities. Many were also uninformed about albinism. The respondents felt that they were more knowledgeable of their condition than many of the medical professions. In any case, even if doctors were less informed of the genetic disposition of albinism, they have no right to bully their patients or treat them as "cases".

“Wonderful”

Others, however, only had praise for the medical profession. “All of my current doctors are wonderful”, says Julie. Five respondents reported being well treated by the medical profession. These participants were mostly consulted by geneticists or ophthalmologists. Their doctors were patient, supportive and optimistic in terms of determining what the respondents could do rather than dwell on their limitations.

My parents saw an eye doctor and I started wearing eyeglasses when I was 13 months and they knew I had a visual impairment because I would fall down the stairs and bang my head...I wouldn't see things...I would walk into things. And the ophthalmologist told my parents just to let me go and that I would have my own limits... I would determine, myself, my own limits. Like they said, “if she falls down the stairs too often, she will be much more careful when she gets closer to stairs”. And I think it's true, you will really determine your own limits.

-Chantal, 44 years-

I was born in Newfoundland in April of 1975. At the time, my parents were living just outside of Harbour Grace. We were not exactly connected with the best and brightest members of the medical community. I was three months old before a general practitioner realised that there was something wrong with me. My mom took me into the doctor for a regular check up, and just before she left, asked if an in-turned eyelash was irritating my eye. When the doctor looked at my eyes he immediately saw that something was wrong. Without saying anything, he ran out of the room and came back with another doctor. While they both looked at me, my mom overheard the first doctor say, “I don't think this baby can see”. Initially, it was thought that I was totally blind. I don't know when they figured out that I could see some. My condition is extremely non-standard. There are a lot of things wrong with my eyes that, to the best of my knowledge, have never been seen with albinism before. Some doctors have suggested that even without the albinism I would still have been legally blind. Anyway, because my case was non-standard, when I go to the doctor usually every doctor and intern wants to look at me. It upsets my mom to have more people than necessary poking at me, but I really don't care. I know that it helps doctors to see as much as possible, especially unusual cases...The doctors I have seen were generally the very best that my parents could find. Right now I am a patient of the only oculogeneticist, and the only geneticist, on the East Coast. I also might have a heart condition related to my eye condition, and so I see a cardiologist as well. All of my current doctors are wonderful. They are really nice, and I have no complaints about them. I have had the same family doctor since I was five and he is always interested to know what I am up to. Whenever I see him we chat for half an hour before the conversation ever gets around to why I actually have an appointment. None of my doctors ever treated me badly, or had disrespect for my condition.

-Julie, 25 years-

The doctors were always aware of my condition before hand. There were never any of those awkward situations where they're assuming that you can see.

-Matthew, 19 years-

For the most part, [doctors] were kind of curious. I think they were as curious about it because many of the doctors I spoke to didn't have any knowledge of albinism either. They were very ignorant of their discipline. However, there was one fascinated guy. When I went to Howard University, there was a doctor named Dr. Ulrich Henschke. He was a German physicist. He had actually set up the Radiation Oncology Department at Howard. And he was actually doing research in Africa on persons with albinism...He had been going over and doing research with sunscreens and bringing them clothes and hats because he had been seeing very nasty, aggressive cancers on these patients...So what he had done was set up a clinic, an albinism clinic in East Africa, Tanzania. So when I first came to Howard, I studied with him, I worked on his research project, and I was supposed to have gone to Africa with him to study medicine. And he died in a plane crash the summer after I graduated and so my travel plans were totally altered, but I was supposed to have been in Africa. So he died in this plane crash and so this never came to pass. He too was very revealing for me because he was the first clinician that I had ever met that really understood albinism and was really working to help on a global scale, to help people with albinism.

-Tyrone, 42 years-

It would appear from the experiences of these few respondents that the medical professions who specialize and are more informed about albinism, display behavior that is supportive and sensitive to people with albinism.

Unfortunately, as reported from more than half of the respondents, not all people with albinism have the opportunity to be consulted by geneticists or other specialists. In many cases, a general practitioner was the only type of doctor in their community. Despite the fact that most general physicians are less informed about albinism, they have no right to maltreat their patients.

PUBLIC MALTREATMENT: “The way they stare.”

All of the respondents reported unpleasant encounters with strangers on account of their albinism. The behavior ranged from open stares to verbal taunts. Many respondents explained that the stares, unlike the verbal remarks, generally did not bother them since most times, they were unable to notice them because of their visual impairment. The participants mentioned that the stares usually affected the friends or family members they were with, more than it affected them.

People look at you. You wait for the bus and people look at you and stare at you...and what's the worst sometimes is that you don't see them and sometimes you do. That doesn't bother me. It bothers, a lot more, my daughters. It doesn't bother my husband... because when you're different, people look at you, but they also look at the people around you to see who is she sticking with and what does the husband look like. Like I'm sure even at work, before I had photos of my family on my desk, I'm sure people were wondering 'oh, my god, what does her daughters look like, what does the husband look like.'

When we're at the store and people stare...especially my eldest daughter, she gets really upset. She doesn't say a word but she says that she finds that these people are so ignorant...the way they stare. To her, that's not right. You don't do that. But I always told the girls “when people stare at me, don't worry. I don't see them, and what I don't see doesn't hurt and it's just because I look different ...it really doesn't bother me.”

-Chantal, 44 years-

People look, but I've learned to ignore the look. A lot of people tell me “I see those eyes piercing through you”. For me, I don't look at it. If people look at me, I'm like “well, I'm flattered”. So I take a different approach to it than a lot of other people do.

-Chris, 18 years-

Verbal taunts

The verbal remarks were most often rude, derogatory, and even demeaning in some cases. Some respondents ignored these comments while others tried to explain what albinism was and the reason for their unconventional appearance. On infrequent occasions, strangers would compliment the female respondents on their appearance.

These compliments mostly came from young girls' fascination with the respondent's hair color.

People...make rude comments sometimes. Once after a high school dance I was at McDonalds with a bunch of people, and this guy came up to me and asked me what colour my pubic hair was. It was very awkward. It was all people from the dance there, but it was the other high school (not my own) so I didn't know any of them. Actually, it happened again a couple of weeks ago. I was out walking with a friend here in Saskatoon and a guy yelled out of a car window, "is all of your hair that colour?" Again though, most of the time people say nice things. I just got back from Calgary, and while I was there over the course of nine days three people complimented my hair, one girl complimented my eyes, and nobody said anything mean. We walked by a couple of guys and one of them said, "she's an albino". I consider that to be a neutral comment. Usually, even the not nice comments that people make are not really mean. They are sort of just stating facts - "that girl has white hair", or, "that girl is really white". Those things are true. I think that those sort of innocent, honest comments mostly bother people who do not like to be noticed, or who are uncomfortable with the attention. They don't really bother me. It is the truth that I am very pale, and that most people have never seen anyone like me before. Sometimes people will say stuff like "it's snow white" or "look at the snow flake", but really there are far worse things that people can call you. I think it would be much worse to be fat and have people constantly calling you a fatty and beached whale. I actually had a teacher call me snowflake, but to him it was an endearing nickname. It is often a matter of the way that people say things, and the way that you take them. I try not to have a chip on my shoulder about my albinism or my disability. A lot of other people with disabilities have developed a nasty chip.

-Julie, 25 years-

When I was younger I would avoid places like the bus or where younger people hang out. I was afraid that someone would say something or make fun of me. As I got older I didn't care as much what people thought so I was okay going out to public places. I still had that feeling that someone was going to say something whether it happened or not. I still get comments from younger kids but for the most part I get compliments. Some people give me dirty looks or I get stared at. Others come up to me and say how beautiful my hair is or they ask me how I got my hair like that. Some other people come up and say really dumb things only because they don't know what to say and they end up feeling embarrassed about what their comment was.

-Amy, 21 years-

I've heard people say that people with disabilities shouldn't be out in public and that they should be locked up. There was one time when there was a bunch of kids who said "hey, Powder!"...That's what I get the most, is jokes about the movie Powder and people think I can fly or something. I kinda just joke with them.

The discrimination is worse when you're with a group of people that's very obvious. Like when I'm walking down the street with a couple of people that all have albinism. It's really easy to notice because you usually don't see a group of people with really white hair and really white skin walking down the street. I've had bad experiences with people yelling and making comments.

Like last summer, we went to Canada's Wonderland, and it was just pouring rain. So, there was about 50 visually impaired and blind people and so we all met up in this one place...we were running and I barely nudged this little kid and I guess it was her father who was helping her just standing there. He started swearing and I heard him say things like "people like that should be locked up and shouldn't be let out" and it really upset me. I was thinking not of myself. I was thinking of all the other friends that I just met. I was thinking, "oh my gosh, he's talking about these people, these are my friends. I don't want him talking like that". I told one of the staff and she explained to him and he said to her "well, if these people can't see they shouldn't be running around". Well, what else are we going to do?

Some of the misconceptions are that people think that Albinism is a disease that they can catch. They think that you have to have pure white hair and pure white skin and pink eyes. And if you have anything else, you don't have albinism. They think that the only thing is white hair and white skin and they don't realize that there is any kind of vision problem associated with it. I've gotten remarks like "She's a demon!" I get these remarks on the street. I get a lot of drunken men saying to me "it's a demon or it's a savior!" and I just ignore.

-Christa, 17 years-

Non-visible disability

Since people with albinism have a non-visible disability, they often experience events where the general public is unaware that they are visually impaired. Thus, my respondents have often encountered rude and insensitive people who implied, through their remarks or actions, that the respondents were either impatient in looking for something or inattentive to their surroundings.

Once I was reading in the bus when I heard a lady next to me, telling two young boys behind me, "you're ignorant". Since I was looking at my book, I couldn't see them making fun of me. That lady was nice to have let them know. There's a French expression saying "Il faut que jeunesse se passe."

Once I was attending a political congress in a big auditorium. People were seated according to the region they represented. The names of the country were written at the back of the chairs and there were so many of them. So I asked a guy if he could tell me where was the one I was looking for. He said "it's right there. All you have to do is search, like me." I thought...maybe he didn't notice my sight was bad.

I must have been twenty years old and I went into a small store to buy a book. I asked the employee of the bookstore for the book I wanted. He said, "it's right there, can't you see?" What makes me mad is when I think I was stupid enough to have bought it anyway. But it doesn't take time to learn how to be a customer and to realize that there are many other stores out there.

-Louise, 47 years-

It appears then, that one reason the respondents endured insensitive remarks from the general public was because strangers were unaware of their visual impairment. People with albinism can be said to have a non-visible disability and thus, it is taken for granted by others that they have perfect vision and, therefore, should not require assistance. Another reason for the often-taunting remarks and open stares is because of the rarity of people with albinism. As Christa points out, "you usually don't see a group of people with really white hair and really white skin walking down the street". In addition, the general public holds many misconceptions about the condition. Thus, remarks such as people with albinism are "demons" or possess "special powers" are often made.

CONCLUDING REMARKS

This chapter has mainly concentrated on the stigma of people with albinism and how it can infiltrate various areas of a person's public life: employment, health care and treatment in public areas. Employers and colleagues were found to be discouraging and disrespecting towards the respondents. Respondents were discriminated against, at the

workplace, because of their physical appearance and visual impairment. Feelings of hurt, aggravation, devaluation and humiliation were expressed.

The medical profession were offensively insensitive and ignorant of people with albinism. Doctors and nurses were also often indefinably fearful of the respondents' condition. For many members of the medical profession, the participants were the first person with albinism they had encountered. Consequently, the respondents were frequently treated as "experiments" or "cases".

The general public was a source of open stares and verbal remarks. Unaware that people with albinism have a visual impairment, my respondents often encountered rude and insensitive people who implied, through their remarks and actions, that the respondents were inattentive to their surroundings.

This chapter, as well as the previous chapter, has focussed on the stigmatization and marginalization that people with albinism face in various areas of their life: childhood, family, intimate relationships, employment, the medical profession and public areas. When taken separately, each example of prejudice could be survived, but the cumulative impact in every sector for their entire lives can be overwhelming. Despite the adversities the respondents have faced, they have developed ways of coping with them. Their coping strategies will be discussed in the next chapter.

CHAPTER 6

COPING STRATEGIES

This chapter focuses on the strategies the respondents have devised in coping with the adversities that often accompany a highly visible physical difference and disability. Eight principal methods of reaction and response to the discrimination against people with albinism can be distinguished. These strategies varied depending on the circumstances of the interaction and the informant's coping skills. These typologies are not mutually exclusive and do overlap. They include: (1) *The Defiant* - those who are quick to respond to insults and are forthright in asserting their rights; (2) *The Activists* - those who are involved in heightening public awareness about albinism in a positive light; (3) *The Serenes* - those who patiently explain their condition to others; (4) *The Internalizers* - those who resent mistreatment but internalize and assimilate their pain; (5) *The Talkers* - those who discuss their adversities with family and friends; (6) *The Hiders* - those who hide their disability to escape prejudice; (7) *The Flamboyants* - those who display themselves and publicly reveal their uniqueness; (8) *The Positivists* - those who have learned to accept albinism as a part of their identity.

As mentioned above, these typologies are not mutually exclusive as respondents have often engaged in more than one of these strategies. However, they tend to specialize in one or two. Each of these coping strategies is discussed below.

The Defiants

Most of the participants were quick to respond to insults. They did not tolerate maltreatment from others related to their physical difference and disability. Instead, they demanded respect and consideration from others. Kim explained that as a child, children

would often harass her. On a bus ride to school one morning, a girl bellowed, “Yuck! Why would you dye your hair that awful color?” Kim simply laughed at the girl and snapped back with a witty response, “for the same reason you dyed your hair that awful color!”

Verbal assertion is not limited to witty replies to insulting comments. It also involves asserting ones rights. Respondents recounted many stories when derogatory comments were directed at them and they assertively stood their ground and voiced their opinion. A few respondents took these circumstances as an opportunity to educate others about albinism.

I deal with people as they come and if they say something ignorant I will assertively but kindly correct them and attempt to educate them on the reality... I am very assertive about my needs. If I am seated in a restaurant in the sun I will ask nicely to be put somewhere shady and say that I have albinism and get burnt easily. I have no problem telling people this. People are always quite accommodating.

-Kim, 30 years-

Now that I am older, I can voice my opinions better and stick up for myself. I still get hurt and distracted when someone says something but for the most part I say something back or stickup for myself when I feel up to it.

-Amy, 21 years-

I have learned to speak up for myself...I may confront people who I think are acting rudely toward me. I have a loud, deep voice and I use it. I let people know that they will not treat me differently because I don't fit into their convenient little box.

-Virginia, 45 years-

I want to be understood and I want people to understand that I am not a push-over, I'm not a wimp, I'm not a person who's just going to be a doormat for other people. I mean, I have feelings, I have thoughts and I have values and opinions that I sometimes want to express. So I had to take an overt position to sometimes be forward enough to do and to say things.

-Tommy, 51 years-

Whereas riposte proved to be a method of dealing with maltreatment for the majority of the sample members, Kim and Chantal also used humor as a way of converting an unpleasant situation into one that was more affable.

I also use my sick sense of humor and often joke about myself in a not too derogatory way. Its amazing how at ease you can put someone when you joke with them about yourself... it helps them understand your situation and lets them know that you don't have a problem with it. For example, I work in a psychiatric hospital as a social worker and people say incredibly honest things to you. I have had one young woman say to me that the other patients were having a bet that my hair was dyed and that I shouldn't worry about the things they were saying. I said to her, "Nah, it's real! I have albinism! See no dark roots!" Others have mentioned my nystagmus, the movement of my eyes from side to side, and I tell them honestly that it is part of having albinism. It can be confronting but it makes you feel comfortable with yourself very quickly!

-Kim, 30 years-

I can laugh at myself very easily... you know, when I walk in posts and stuff. It happens sometimes that I'm walking in the mall and the post is the same color as the floor. When there's no contrast sometimes, it can make you run into something. I can laugh at that.

-Chantal, 44-

The Defiants are successful in their everyday endeavors, including their jobs. Of those who had experienced derision at the workplace, the respondents made it clear that verbal abuse was simply not tolerated. They have all asserted their zero-tolerance policy to contempt.

The Activists

The misconceptions about albinism are staggeringly abundant. Five of the participants are vocal members of the National Organization of Albinism and Hypopigmentation (NOAH). At the 2000 NOAH conference, Tyrone presented a workshop titled "Are you Talking to Me?" which focused on anger management and strategies for effective communication. In addition to being an active member of NOAH,

Kim has participated in photographer Rick Guidotti's *Positive Exposure* worldwide project that aims to "open our eyes to the beauty of albinism", through photography (Guidotti, 1998:65). Chris and Chantal are also actively involved in various organizations for people with disabilities including the Montreal Association for the Blind, and the National Organization for the Blind. Virginia has taken a different approach by creating an Internet website relating historical facts about people with albinism.

I cope by trying to help others who are in the same situation I am in. I don't want anyone to grow up thinking they are alone on this planet the way I did. I talk with others over the phone and Internet, answer their questions and hook them up with others like us. I have started a website just for us where people can go and get information and historical facts. This helps me as much if not more than anyone else.

-Virginia, 45 years-

[Albinism] has made me down to earth. It has given me an empathy for others that I don't feel that I would have to this extent if I didn't have some form of difference. I have a passion for advocacy, standing up for those people who don't have much of a voice... I have gone on TV and on radio and done public awareness interviews at different times. I have also worked with Rick Guidotti, all to raise public awareness. I think is cool!

-Kim, 30 years-

These five activists fervently believe that heightening the awareness about albinism is the key to challenging the stigma of difference. The more information on albinism available to the public, the more people will be respectful of the visual disability and unconventional appearance of people with albinism.

The Serenes

Three of the sample members displayed much patience as they willingly explained their condition to others when asked. The participants continuously maintained

that when asked politely, they were extremely tolerant of the numerous questions they were posed, as they understood the rarity of albinism and its unfamiliarity to the public. When Tyrone was bluntly hailed "Hey, albino!" by a teenager on the street, he immediately seized the opportunity to educate him.

I may say "excuse me, what did you say?" And then I'll use it as an opportunity to teach because I need to explain to them "you may know what the word is, but you don't understand what it really means." And I would tell them that a person is not an albino. A person is a person with albinism, which is a condition where we don't have pigments. And I would go on to explain about "I'm black just like you are except my color's on the inside while yours is on the outside. That doesn't mean we're not the same."

-Tyrone, 42 years-

For many people in public, the respondents may very likely be the first person with albinism he or she may have encountered. Therefore, they are often uncertain as how to interact with or react to people with albinism and the physical differences they possess. Julie and Matthew explain how they manage adverse encounters with keen understanding and serenity.

When people approach me about how I look I try to be as polite and friendly as possible. I just say thank you when they complement my hair or my eyes. Lots of time my eyes look dark purple. If they ask questions I answer them as briefly as possible. Most people do not want extended medical descriptions of things. If they want medical information they ask for it specifically, and I will give it to them then.

I am the only person with albinism that most people will ever meet. Sometimes I am the only visually impaired person that people will ever meet. I try very hard to be understanding of people, help them learn to approach differences in others more appropriately, and make their experience meeting me positive. Lots of people are afraid to talk or interact with people who are different because they are afraid they will be politically incorrect and they don't know how to act...Understanding of people is very important. If you try to understand why people react the way they do it won't bother you so much. The truth is that I would probably stare at me too, especially if I didn't know what albinism was or had never seen it before

-Julie, 25 years-

I explain to people what I do know about my condition, which isn't very much...I know very little about it...but what I do know I explain to people. [Being discriminated against] angers me a little bit but I've always been able to just explain to people. And that's about all I can do.

-Matthew, 19 years-

Tyrone, Julie, and Matthew attributed their inner serenity to the acknowledgment that many people are not well versed about albinism. Even Matthew admits that he is not highly knowledgeable about the genetics of albinism. Yet, he emphasized the necessity of explaining the facts about albinism, no matter how brief, to others who are genuinely interested and concerned.

The Internalizers

The Internalizers are those respondents who resent mistreatment but internalize their pain. The respondents indicated an awareness of the often-taunting remarks made by others, but explained that it was easier to remain subdued and internalize their emotions, rather than to assert their feelings.

I am usually quiet and reserved. I probably internalize many things rather than let it out. I am working on that...I have learned to roll with the flow and not let things bother me too much. Although I do tend to think about things and turn them over in my head too much. I just work hard at being the best that I can be and show, through my actions and deeds, who and what I am.

-Bergess, 43-

Usually on the spot, there are two phases to my madness. On the spot, I'm pretty good with it and for some reason I won't react to it. After I've left the situation it will hit me at that point and then the anger will come out... Afterwards I deal with it differently which I don't know if it's so much of a good thing because I'm thinking, "if there's some kind of stupidity going on where discrimination is taking place or where people are being idiots about it, honestly, they should be sensitized about it or confronted with it right away". And in my case, it doesn't click right away. They're going to continue on their merry sweet way and continue this. It doesn't really solve anything in the long run.

-Chris, 18 years-

The Internalizers acknowledged the drawback of internalizing their pain rather than being able to openly express their feelings. Chris and Bergess maintain that they are constantly trying to engage in being Defiant in situations where they are targets of discrimination. They unveiled the fact that allowing others to debase them sends the incorrect message that they are tolerant of the maltreatment. In reality, The Internalizers resent the maltreatment and want to fight back. Thus Chris and Bergess continue to develop their self-confidence and assertiveness in order to voice their opinion the next time that they are confronted.

The Talkers

Family was a safe haven for all of the respondents. Chantal, Chris and Kim diffused their pain and anger by sharing it with their families. Parents, siblings, spouses and children were endlessly supportive of the respondent's situation and were a source of unconditional love and solace. The Talkers were similar to The Internalizers in that they were reserved at the moment of confrontation and remained silent. However, The Talkers did differ in one way. Once withdrawing from a confrontation, they returned home and discussed their anguish with significant others. The Talkers emphasized the importance of "communication" amongst family members. Chantal recounted her sentiments, "I talk about situations with my family...we communicate a lot". Chris and Kim explain the benefits of having adopted this strategy.

Often I'll discuss it with other people. My family, in my case, is very understanding of it. I can always come back and say, "you wouldn't believe what happened today" or "do you now what these people did?" I'm very lucky that way. They're always there.

-Chris, 18 years-

As a child I would deal with it by talking to friends... and my parents. They treated me normally and encouraged me in joining drama classes for many years which provided escapism for me from school.

-Kim, 30 years-

For the three respondents, sharing sorrows and triumphs with significant others were means of uplifting their spirits on days that they encountered adversities. Rather than internalizing their pain, they were able to unload their concerns and distress while being assured undivided support in return.

The Hiders

For two of the sample members, the pain of oppression was intensely unbearable. In some instance, they felt the need to conceal their disability to escape discrimination. For Tommy, the excessive taunting has precluded him from reading in public. He used to be the target of rude remarks pertaining to the manner in which he placed reading material close to his face.

I think the worst thing is reading. If there's anything I have to read, it becomes a little bit more apparent that I have difficulty seeing. I have to bring things very close to me and for years I never read in public. I didn't like to read in public because people would look at you as if, "damn, is it close enough?" ...or "how much closer do you need it?" People would say things like that. People, they think they're cute. They'd say "why are your glasses so thick?" They just say what they think, but they don't realise the weight that their words have for not making a person feel comfortable in any situation. I wouldn't have put the material as close to my face if didn't need to read but people don't think like that. They're amazed that "You're so different than I am" and "My god! What the hell happened to you?" That sort of mentality stays there, and it comes right out of their mouth without even thinking.

-Tommy, 51 years-

It is important to point out the role of the Other. In these circumstances, the normal rules of civility and courtesy do not apply. The others do not think before they act.

As a teenager, Chantal was self-conscious toward the manner in which her school friends would regard her. She explains her strategy in concealing her disability in order to avoid discomfoting situations.

When you're younger, you tend to hide your disability. You don't want it to show and...when I was 13 or 14, I used to go out with my friends and I didn't wear my glasses because they were too thick because then they didn't have the technology to make the thin lenses. I would put my glasses in my pocket, not to look different. But, obviously, that didn't change anything...the low vision was still there! That was one of the ways I'd try to cope so that people wouldn't look at me differently.

-Chantal, 44 years-

However, Chantal has developed other strategies over time.

In situations of unendurable mockery and taunting, concealing one's disability is often a method that people with albinism resort to. In such instances, respondents can be viewed as attempting to "pass" as a person without a disability to avoid maltreatment (Goffman, 1963:42). "Because of the great rewards in being considered normal, almost all persons who are in a position to pass will do so on some occasion by intent" (Goffman, 1963:74).

The Flamboyants

Julie was the only sample member who reveled in her conspicuousness and publicly revealed her uniqueness. Julie displayed herself flamboyantly by wearing short skirts and has recently dyed a streak of her "platinum blonde hair", blue. She receives many comments, especially from young girls regarding her "Barbie doll" like hair. To

others, she is strikingly noticed. "Once, I got head turns from six to seven cars out of every ten cars that passed" she explains. She insists that the attention she receives is positive and that she enjoys being "different from other people."

"Guys notice me a lot because I stand out. I have platinum blonde hair nearly to my waist, I am 5 feet 7 and weigh 105 pounds...One summer in particular, I went out a lot and it was a slow night if I only met one guy. The guys were generally good-looking...obviously the sort of guys that went to the bar on a trophy hunt. I totally ate the attention up too."

-Julie, 25 years-

This strategy of flamboyance is interesting because it defies the conventional norms of camouflage by covering up physical differences in order to avoid being noticed. This technique is opposite to The Internalizers or The Hiders that have been previously discussed. Flamboyance is an assertive self-display. It's in your face.

The Positivists

Verbal defense and political activism are ways of dealing with discrimination against people with albinism. Unconditional acceptance of oneself is the valued asset a person can rely on to fight against external prejudice. All of the sample members have been Positivists at some points of their lives; Julie, Tyrone, Chantal, Amy, Louise and Kim are the sample's most obvious Positivists. The Positivists felt that albinism has become a significant determinant to their uniqueness and authenticity. The Positivists and The Serenes share similar coping skills as they believe that explaining their condition is a way of informing others about albinism. However, the Positivists differ in that they are generally older than The Serenes. The Positivists have acquired years of experiences in which they have learned the skills to cope with adversities. These skills have contributed to their positive attitude.

Despite the daily adversities they have endured, The Positivists have suffered the least because they were the most secure with themselves and with what they had to offer as people. The Positivists spoke at length about the importance of accepting and loving oneself as they are. They simply viewed their physical differences and disability as a variation of the human population and recognized their uniqueness. In contrast to many of the other participants, they tackle adversities with an entirely positive attitude.

I cope one hundred percent positively with it...I very seldom have bad days...I've always accepted myself and I'm a very positive person. I'm just so happy.

-Chantal, 44 years-

Tyrone copes with the adversities he has faced with much optimism. He is the sole member who attributed his inner serenity and acceptance to the fact that he is deeply spiritual and focuses his energy on positiveness rather than dwell on the negative. He explains his strategy of managing adversity.

[I] turn every challenge into an opportunity. For me, it's guided more so by a deep de-rooted sense of self. I know who I am, I know I have value, I know I have worth. I'm not a Holy Roller in a sense that I'm going to start spouting the bible at everyone, but God is very much a part of my life. I know that there is one absolute and supreme truth and that gives me a sense of focus. So when I go through life, I focus more on the positive and not the negative. I tell people too, that you have to learn how to process the negativity. People will sometimes take negative situations in and they let them just reside there. But what I try to do is take a negative situation and you process it. If it's going to add to your self-worth and if it adds to life, then hold it. But if it's something totally negative or destructive, then you don't even have to process it. Just let it go through.

-Tyrone, 42 years-

To deal with having albinism I have needed confidence, acceptance, understanding, and a friendly attitude...It takes a significant amount of confidence to be different. Often people have the choice to be different. It is something that they want to be, and they work hard at it. They get tattoos and outrageous piercings, or do crazy stuff to their hair and clothes. I think that problems arise when difference is thrust open people who are not prepared to deal with it. With albinism you don't have the choice to be different. You are on display whether you like it or not. People's attention is naturally drawn to you. That is

hard for shy people to deal with. You can't be anonymous and just blend in when you are an albino. Acceptance is important too. If you accept the way you are and are proud of it you get a lot further. You don't waste time brooding about something that can't be changed. I like having albinism. I like being different than other people. The difference between being a freak and unique is subtle, but important, and it's mostly a matter of attitude.

-Julie, 25 years-

The Postivists were also forthright in explaining the importance of turning all obstacles into an opportunity to be sought. This attitude is assumed to have largely contributed to the fact that they were all successful in various areas of their lives including their careers and intimate relationships.

Four of the six Positivists possessed abounding acceptance for themselves and felt the necessity to help others. They eloquently recounted that the adversities they have endured have forged them into, emotionally, “stronger” people. They have experienced at firsthand, discrimination, prejudice, mockery and taunting. The maltreatment has heightened their awareness of the feelings and anguish of people with albinism, thus resulting in their eagerness to help others.

I have gone through a lot of hurt and pain. I have gone through many examinations and stress and strain in school. My self-esteem has been put through the floor and I have been uncomfortable with my looks. All of this I think is a life experience. I am not the only one out there that had to go through that kind of stuff. I am a stronger person because of my condition and all the baggage that comes with it. I just have to accept me for me and move on. There is no use in dwelling on my condition and feeling sorry for myself cause I can't change it, it isn't going to go away, it is here for life so I have to deal with it. There are many times that I wish I wasn't me but I can't change it. In that I mean I would love to have perfect vision or brown hair or a nice tan for just one day. Overall, I am happy to be alive and I love everyone who has helped me and been there for me. Now that I have gone through college and am in the Social Work field, I can help others so I can give the help back to others. I want to help people for once instead of people helping me. I can relate to other people who need help so I want to be there for them.

-Amy, 21 years-

In terms of coping day to day, I think my attitudes have changed more now than the last five years given divorce, and really understanding what the point of life is. To me, the most important things in life are faith, family and health. And peace of mind is absolutely essential. Actually, I'm not so worried about the negative. I know that there are only so many hours a day and I can only do so many things. I strive to help people where possible. I try to be authentic. I try to reveal a genuine sense of who I am and I try to speak with what I call, radical honesty, and try to be truthful in all my endeavours and encounters. I find that's the formula that really works well and it helps to establish a sense of calm and peace at other people. It also helps to build confidence and trust.

-Tyrone, 42 years-

In my mind, it's not my fault there are things that are more difficult to do, or things that take more time to do than others. But it's not anyone else's fault either and, in any case, I shouldn't be mad or impatient at someone who doesn't feel like helping or just doesn't have the time to help because they are in a hurry...I don't feel they owe me anything just because of my handicap. What's good for me is when I can do things for other people. Helping, not only being helped.

-Louise, 49-

[Having albinism] has given me strength to face most things life can dish out, so far, as I had a rough school life. So, anything that comes my way now I can handle easier. I didn't lead a protected life so bad times don't get me down as much. I have met amazing people with albinism and it has given me the opportunity to give them encouragement from a first hand point of view. They can see that you can get through school and lead a normal life. I also think that the friends that I have made are real friends as it was harder for me to make friends. Superficial people wouldn't hang out with me, so I got all the genuine people as my friends, and they are very close and life long. I also love my hair color and don't have to dye it to get it to the color that others use peroxide to get. I love being unusual and unique. I now believe that having albinism is a blessing rather than a hindrance and welcome any opportunities to use it to my benefit to help others.

-Kim, 30 years-

Self-acceptors have shown to be comfortable with their physical differences. They have accepted that aside from their disability and differences, they could lead productive, fruitful lives. Many have even chosen to assist others in need. As Julie articulates, attitude is the determinant of how one conceives oneself. "The difference between being a freak and unique is subtle, but important, and it's mostly a matter of

attitude". The respondents have shown that despite adversity, true and total self-acceptance, along with a positive attitude, can triumph over affliction.

CONCLUDING REMARKS

People with albinism resist the stigma of difference. They fight back at the derision and mockery they often encounter, in a variety of ways. Some are quick at responding to insulting remarks and hold a zero-tolerance policy to imprudence, some engage in political activism as they fervently believe that heightening the awareness of albinism will challenge the stigma of difference, and some are openly flamboyant and display their differences with pride. While these respondents displayed attitudes of verbal assertiveness, there were those members of the sample who were contemplative in their method of resisting against the frequent adversities they were faced with.

Contemplative resistance was effective for those respondents who exercised the coping strategies of positivity, serenity, and conversing with significant others. The Positivists were adept in shrugging off any prejudice of albinism as an issue that failed to affect them. They have a solid sense of security, self worth, and self-identity that has shown to withstand even the harshest types of bigotry. This grounded sense of self can be attributed to the unconditional love and support from their families, and their positive attitude that colors all aspects of their lives. The Serenes are keenly aware that albinism is a condition unknown to many because of its rarity. With this understanding, the respondents are tolerant of the many questions regarding albinism, and they respond with serenity and patience. The Talkers have found their families to be a source of endless support. It is with their family members that they able to unload their adversities with the assurance of being accepted unconditionally.

Not everyone can resist, however. Learning the skills to managing adversity as the active and contemplative resisters have done, requires time. The Internalizers fail to assertively voice their opinions at the moment of confrontation. Instead, they internalize their pain and feel angry. For the Hiders, the derision is so overpowering that they feel the urgency to hide their disability to escape prejudice. Both The Internalizers and The Hiders wish to assert their rights and fight back. Thus they are continuously developing the skills to learn the effective coping mechanisms that would allow them to express their views, without reserve.

These eight different types of responses and reactions to resistance to the stigmatization of albinism are essential elements of personal change and, even possibly, social change. People with albinism have developed these coping mechanisms at various circumstances throughout their lives. These typologies should not be regarded as mutually exclusive since, in some instances, the most serene respondents have defended themselves with verbal assertion, while on other occasions, the more assertive participants have found themselves remaining silent; and the dominant strategy may change over time.

CONCLUSION

SUMMARY OF FINDINGS

The twelve respondents who participated in this study have voiced their experience of what it is like for people with albinism to have a strikingly unconventional appearance as well as a visual disability and, at the same time, live in a society that discriminates against physical difference and impairment. Their stories and experiences have revealed that people with albinism are stigmatized and marginalized in many areas of their lives; but also that they have developed coping mechanisms to manage the adversities they are faced with.

The family setting is a place that all my respondents recall being a safe haven. Family members were supportive, accepting and understanding of the respondents' condition. Parents displayed feelings of pride and joy for their children with albinism and constantly encouraged them to participate in activities that other children were a part of. The respondents recall that their parents played a key role in helping them understand and accept themselves, with albinism. However, as the respondents grew older, they soon learned that the world beyond their front door steps made them feel that there was something unacceptably different about them.

As the respondents enrolled in mainstream Elementary Schools, they endured name-calling as well as physical forms of victimization. Both teachers and students were the source of mockery and derision. In most cases, the respondents were left with feelings of loneliness and isolation. As the respondents moved on to High School, they experienced reduced levels of discrimination related to having albinism, and received more positive treatments from teachers and students. This made "fitting in" much easier

for the respondents. Many students were even fascinated by the respondents' appearance. However, dating was a difficult experience. Forming intimate relationships was a challenging task because of their appearance. Generally, however, the transition from childhood to adolescence brought about a positive transformation whereby the respondents were accepted rather than rejected.

Adulthood has not alleviated the pain of being discriminated against and marginalized. Respondents report having been discriminated against at the workplace because of having albinism. Both physical appearance and visual impairment are reasons for the prejudice they endured. The majority of the respondents indicate that they were disrespected and rejected by both superiors and colleagues. Furthermore, having albinism may reduce the chances of marriage, as the majority of the adult sample is unmarried.

Doctors and nurses were found to be excessively ignorant and insensitive towards the respondents. The majority of the respondents experienced being treated as a "new case" or "experiment" by the doctors. Many of the physicians were also very pessimistic concerning the respondents' condition, and often discouraged them by emphasizing their disability and limitations. Ironically, many of the respondents felt that they were more knowledgeable of their condition than many of the medical professions.

Respondents were also prone to unpleasant encounters with strangers in public areas, on account of their albinism. The behavior ranges from open stares to verbal taunts. Since people with albinism have a non-visible disability, they often experience unpleasant remarks from others as the general public is often unaware that people with albinism have a visual impairment.

In summary, these findings show that people with albinism constitute a minority group who are identifiable by physically distinguishable characteristics and are treated differently from those who do not have albinism in regards to the opportunities made available to them. Despite the many adversities they are faced with, people with albinism develop coping mechanisms. In analysing the participants' responses, this research has identified eight principal methods of coping with the discrimination against people with albinism: *The Defiant*, *The Activists*, *The Serenes*, *The Internalizers*, *The Talkers*, *The Hiders*, *The Flamboyants*, and *The Positivists*. These eight different types of responses and reactions to resistance to the stigmatisation of albinism are essential elements of personal change and, even possibly, social change. People with albinism have developed these coping mechanisms at various circumstances throughout their lives.

Certain strategies are developed in order to adapt to the major environment; school, workplace, medical profession, and intimacy. To avoid discrimination, people with albinism often conceal their visual disability from the general public. They attempt to present themselves as "normal", as have *The Hiders*. Goffman's theory of stigma refers to this as "passing" or concealing discrediting information about the self in order to be treated as a "normal" rather than an abnormal.

While some attempt to hide from society, others place their efforts in changing society. *The Activists*, for example, serve as advocates and heighten public awareness of albinism. In line with the Disability Studies approach, they are aiming for inclusion.

Then there are those who are extremely tolerant of various forms of discrimination. *The Serenes*, for instance, possess an inner serenity that allow them to patiently explain and dispel the misconceptions that others have about people with

albinism, and then be on their merry way. Such carefree attitude is yet another strategy of managing daily adversities faced by people with albinism.

These different strategies of reaction and resistance reflect the theoretical insight of both Goffman and the new Disability Studies. Goffman has emphasised both the presentation of the self and the concealment of self in his work while the new Disability Studies has problematised Goffman's "normals" as have The Activists in their resistance against the stigma of difference. Both theoretical orientations are useful in explaining the various orientations of people with albinism.

My research findings have brought me to conclude that, despite the discrimination and oppression that people with albinism experience in various areas of their lives, they resist the stigma of difference and disability. My respondents have shared their life experiences: their sorrows and their triumphs. They have experienced and emerged from crises and hardships. They express how these difficult times have built them into internally powerful people living extraordinary lives. From albinism as "novelty", "me", "special", and a source of "pride", to being "not different" and "genetically inconvenient", it is evident that my respondents related the notion of their identity to the construction of their bodies. They have positively identified with their differences and uniqueness, and refuse to view their condition as a disability. Despite being frequently shunned by society, their positive attitude and strong will to accomplish their goals has allowed them to recognize their inner attributes, and triumph and overcome adversity. They have discovered that their life journey with albinism not only poses barriers, but also brings about opportunities for achievement.

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APPENDIX : Sample Interview Questions

1. What does albinism mean to you?
2. As a child growing up, you must have experienced some discrimination. Tell me about your experiences.
3. How did/does your family/relatives react to your condition?
4. Tell me about your experiences at school. How do students and teachers treat you? Describe some of the times you were discriminated against.
5. If you work or have worked before, have you experienced discrimination in the workplace? Discuss some of your experiences.
6. Are you married or in a romantic relationship (dating)? Discuss some of your feelings about this issue.
7. How do/did people in the medical profession (doctors and/or nurses treat you in relation to you having albinism?
8. Tell me about some of your experiences with discrimination or adversities you have had to face in public areas.
9. How do you cope with the discrimination or adversities you are faced with?
10. How has having albinism made an impact on your life?