

‘Orange in a World of Apples’: the voices of albinism

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ABSTRACT *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 impairment. 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 paper attempts to remedy this failure in social science.*

In-depth interviews were conducted with seven women and five 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 these adversities. The results identify eight principal methods of reaction and response to the discrimination against people with albinism.

These eight different strategies of resistance to the stigmatisation of albinism are essential elements of personal change and even, possibly, social change. This paper quotes respondents’ own words. Such methodology offers the chance for people with albinism to voice their experiences, and for us researchers to listen and learn.

Introduction

This article gives voice to people with albinism as they recount the negative social repercussions they face in societies that marginalise and stigmatise people with an unconventional physical appearance and an impairment, and the strategies they develop to cope with such discrimination and prejudice.

Albinism is a rare genetic condition that affects the pigmentation of the retina, hair and skin. In the United States, one person in 17,000 has albinism giving a total

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of about 16,000 individuals National organisation for Albinism and Hypopigmentation (NOAH, 2000). Due to its rarity, people are often ill-informed about people with albinism. Consequently, people with albinism world-wide experience the negative repercussions of an unconventional physical appearance, as well as a visual impairment.

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 semi-outcasts; they participate less in daytime tribal activities and are not permitted to marry (Witkop, 1975, p. 1).

In parts of Africa, people with albinism are treated like outcasts from birth. As white-skinned men and women in predominantly black societies, they are shunned and even murdered as they are feared to be products of witchcraft (McNeil, 1997). Zinhumwe 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 infectious. We are generally treated like second-class citizens' (1996, p. 1).

In North America, the prejudice is also apparent. 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. Also Hollywood's tradition of equating albinism with evil ('Albino') or alien ('Powder') demonstrates that prejudice towards persons with albinism is socially acceptable.

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 stigmatised 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' (1995, p. 140). It seems that what gives stigma its intensity and reality is fear of the unknown.

This paper attempts to illuminate a relatively under-studied and ignored domain in sociology. There has been almost no attention paid to how people with albinism cope with the virulent stigma that often accompanies this condition. The lack of research into the life stories of people with albinism is an illustration of their exclusion and marginalisation. To remedy this failure in sociology, this paper seeks to understand how people with albinism cope with the social stigmas of a physical impairment and an unconventional appearance. It seeks such understanding through the direct testimony of people with albinism.

First, we look at the methodology; secondly, we consider the theoretical framework; thirdly, we discuss the problems; and finally, we review the coping mechanism that the subjects have developed to manage discrimination.

Methodology

Twelve people, seven women and five men, participated in this study. The sampling design was conducted in a snowball fashion, whereby each interviewee was asked if he or she knew someone else with albinism who would be interested to talk with us. The Montreal Association for the Blind (MAB) was also contacted for respondents.

Since albinism is a rare condition, searching for participants with albinism was a relatively difficult task. Many interviewees are the only ones in their family who have albinism, and few socialise with people with albinism as they do not live in a community where there are others with albinism. The only occasion when they do meet others with albinism is the conference held by the National Organisation for Albinism and Hypopigmentation (NOAH) in the United States.

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. Respondents included individuals from Canada (Montreal, PEI, Saskatchewan, and Quebec, City), the United States (Connecticut and Washington DC) and Australia (Sydney; see Table I for personal characteristics of respondents).

The visual acuity of the respondents ranged from 20/100 to 20/500. 20/200 is considered legally blind (Webster & Roe, 1998, p. 23). Of the 12 respondents, 11 wore prescribed eyeglasses. All the participants used other vision correctional devices including monoculars, magnifiers, laptops with large print software (Zoom-Text), large print books and bioptic equipment.

Data was collected using open-ended, semi-structured interviews. Semi-structured interviews provided the latitude to probe pertinent topics deeply. The questions revolved around their personal experiences, both positive and negative, and the coping mechanisms subjects may have used to deal with the stigma of physical difference and visual impairment.

The interviews averaged one-and-a-half hours in length, and all were conducted in one session. 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.

One caveat is in order, namely that this is not a representative sample since the sample size is small, and it includes a relatively large number of middle class respondents and activists. Therefore, the results cannot be generalised to the larger population of persons with albinism.

The objective of this study is to provide an overview of the adversities that people with albinism face and the mechanisms they develop to deal with them.

Theoretical Framework

Erving Goffman's Stigma

Cognitive and perceptual processing of human body differences is universal. How-

TABLE I. Personal characteristics of respondents

Name	Age	Sex	Residence	Visual Acuity	Occupation	Marital Status
Christa	17	Female	PEI, Canada	20/200	Student	Single
Chris	18	Male	QC, Canada	20/120	Student	Single
Matthew	19	Male	QC, Canada	N/A	Student	Single
Amy	21	Female	BC, 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	QC, 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 DC, USA	20/140	College administrator at university	Divorced
Burgess	43	Male	Connecticut, USA	20/200	VP marketing	Divorced
Louise	49	Female	QC, Canada	20/200	Quality control agent	Single
Tommy	51	Male	Washington DC, USA	20/200	Public school educator/musician	Married

ever, 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 impairment a sociological topic in that he speaks of societal reactions to 'abominations of the body'. He suggests that all human differences are potentially stigmatisable and may be devalued by wider society. For Goffman, stigmatised 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, 1963, pp. 3, 4)

Goffman refers to the others who possess the potential to stigmatise 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 utilising stigma terms to further demoralise the stigmatised, the normals have a tendency to 'impute a wide range of imperfections on the basis of the original one'. In fact, the stigmatised 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, p. 5). This is known now as the 'horns effect' (Synnott, 1993, p. 74). In studying the power of beauty and ugliness in society, researchers 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 (Bersheid & Walster, 1972, p. 74; Synnott, 1993, pp. 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 stigmatised individuals who assume that their 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, stigmatisation 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, p. 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, p. 74).

Goffman contends that 'visibility' of a particular stigma is a 'crucial factor' when determining whether an individual is to be stigmatised against or not (Goffman, 1963, p. 48). Attributes such as skin colour and particular physical impairments 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.

While the visibility of some stigma preclude the option of passing, some discredited traits can be 'covered' and 'concealed' (Goffman, 1963, p. 102). One

type of covering can be done, 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 impairments 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 through which conversations are organised (Goffman, 1963, pp. 103, 104).

Goffman is insightful about the visually impaired and blind people; indeed, people with albinism have a condition that Goffman would deem a stigmatised condition. In fact, people with albinism have a double stigma: the colour 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.

However, there are serious flaws with Goffman's theorising of stigma. He did not discuss any strategies of reaction other than passing, nor does he discuss the vital issue of resistance. Furthermore, he seems to regard all stigmatised people as having 'spoiled identities', which is clearly not the case, as we shall see. Nor does he ever critique or interrogate 'the normals' for their prejudicial attitudes and discriminatory behaviour.

Disability Studies

Research in the field of disability has evolved as a way of addressing how people with impairments have been treated historically and how they continue to be treated. From around the 1920s, 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, p. 2). The medical model of disability played a role in the segregation of people with impairments, and in the labelling 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 impairments (Monaghan, 1998, p. 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 stigmatising society.

Then, in the sixties, impairments began to be seen through a sociological model which focuses on the stigmatising process (e.g. Goffman, 1963) and through a

psychological model, where their experiences have been individualised and pathologised (Harris & Lewin, 1998). This latter approach envisions impairment as a physiological problem or a set of unfortunate individual circumstances in need of solutions offered by medical interventions or social work. Brendtro et al. have described how, at different times, and in different cultures, impairment 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 impairment perceived disability as misfortune, as sickness, as 'other', as punishment and as a threat (Woodill, 1994, p. 209).

More recently, people with impairments are being viewed through different lenses. The new Disability Studies movement from the eighties offers a conceptual framework whereby impairment is viewed as a social construct. The sociological model of impairment stresses a framework for understanding impairment as resulting from the effects of society geared towards able-bodiedness as the norm, rather than a person's physical, sensory or mental impairment. Abberley (1987) 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 impairments from exercising their rights. Abberley notes that 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 impairments and has, therefore, become prominent in the field.

Impairment, 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 do 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 & 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 problematise society rather than the individual (Harris & Lewin, 1998). The solution lies not in the person with the impairment, but in the persons without the impairment, and in removing the barriers that limit people with impairments participating fully in their communities and in society in general.

The new Disability Studies are about inclusion and also power. In this framework, eliminating social and physical barriers that create impairment 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 impairment (Rioux, 1994, p. 5). It is clear, then, that there has been a shift from Goffman's theory of 'spoiled identity', whereby people with impairments are stigmatised by the 'normals', to the Disability theory of 'identity spoilers' who are the 'normals'. The new Disabilities Studies not only calls for the inclusion of people with impairments 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 misrecognised (Thomson, 1998, p. 1).

Sources of Discrimination

People with albinism are stigmatised and marginalised in many areas of their lives: childhood, intimate relationships, employment, medical profession and in public areas. Yet, they have also 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. Tommy recounts his family's supportiveness:

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, and 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 ...

Yet as the respondents grew older, they soon learned that the world beyond their homes was not as accepting of their albinism.

As the respondents enrolled in mainstream Elementary Schools, they endured name-calling, as well as physical forms of victimisation. Both teachers and students were the source of mockery and derision. In most cases, the respondents were left with feelings of loneliness and isolation. '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. 'Whitey', 'Powder', 'Ghost' and 'Casper' are just a few of the derogatory names that children called them. 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. Christa recalls her experiences:

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?’

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.

Many of the respondents expressed their frustration, as teachers were insensitive to their needs. Respondents claimed that they were capable of completing 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” ’.

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. Teachers were more understanding of their visual difficulties and other children and teenagers were simply curious about their physical appearance and posed questions regarding color of their hair and eyes. 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’.

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.

Dating, however, was difficult during the teenage years because of their appearance, but such difficulties seemed to ease up later in life. Some people experienced derision, others found 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 eloquently put it, ‘I feel like an orange in a world of apples’.

Adulthood has not alleviated the pain of being discriminated against and marginalised. More than half of the respondents reported having been discriminated against at the workplace because of having albinism. Both physical appearance and visual impairment were reasons for the prejudice they endured. The majority of the respondents indicated that they were disrespected and rejected by both superiors and colleagues. 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. Amy expresses her fear of rejection:

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.

For people with albinism, visual impairment is of most concern when being hired for a job or when performing the tasks required for a job position. 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.

Doctors and nurses were found to be excessively ignorant and insensitive towards the respondents. 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 Burgess 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'. Chris reports how one optometrist was insulting and a doctor 'who was actually scared of touching me ... and another was shaking'. 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.

Respondents were also prone to unpleasant encounters with strangers in public areas, on account of their albinism. The behaviour 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. Louise explains her experience:

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.

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.

Coping Mechanisms

Despite the many adversities they are faced with, people with albinism develop coping mechanisms. Eight principal methods of reaction and response to the discrimination against people with albinism have been identified. These eight coping strategies have been drawn from this study alone and the labels were formed from the subjects' quotes. These strategies vary depending on the circumstances of the interaction and the informant's coping skills: also these responses are not mutually exclusive and do overlap. They include:

- *The Defiant*—those who are quick to respond to insults and are forthright in asserting their rights;
- *The Activists*—those who are involved in heightening public awareness about albinism in a positive light;
- *The Serenes*—those who patiently explain their condition to others;
- *The Internalisers*—those who resent mistreatment but internalise and assimilate their pain;
- *The Talkers*—those who discuss their adversities with family and friends;
- *The Hiders*—those who hide their disability to escape prejudice;
- *The Flamboyants*—those who display themselves and publicly reveal their uniqueness;
- *The Positivists*—those who have learned to accept albinism as a part of their identity.

As mentioned above, these approaches are not mutually exclusive as respondents have often engaged in more than one of these strategies and also some change their tactics over time. However, most people tend to specialise in one or two tactics, depending on their personalities and circumstances. Each of these coping strategies is discussed below.

The Internalisers

The Internalisers, Chris and Burgess, particularly are those respondents who resent mistreatment, but internalise their pain. These two men indicated an awareness of the often-taunting remarks made by others, but explained that at the moment they were being humiliated, it was easier to remain subdued and internalise their emotions, rather than to assert their feelings. Burgess describes his coping strategy.

I am usually quiet and reserved. I probably internalise 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.

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

The Hiders

For Tommy and Chantal, the pain of oppression is intensely unbearable. In some instances, they feel 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.

In situations of unendurable mockery and taunting, concealing one's impairment 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 an impairment to avoid maltreatment (Goffman, 1963, p. 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, p. 74).

The Talkers

The family is a safe haven for all of the respondents. Three respondents diffuse their pain and anger by sharing it with their families. Parents, siblings, spouses and children are endlessly supportive of the respondent's situation, and are a source of unconditional love and solace. The Talkers are similar to the Internalisers in that they are reserved at the moment of confrontation and remain silent. However, Talkers do differ in one way. Having withdrawn from a confrontation, they returned home and discussed their anguish with significant others. The Talkers emphasise the importance of 'communication' amongst family members. Chris explains the benefits of having adopted this strategy:

Often, after I've had an unpleasant encounter with someone, 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 know what these people did?' I'm very lucky that way. They're always there.

For Chris, Kim and Chantal, 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 are able to unload their concerns and distress while being assured of undivided support in return.

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 impairment. 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. Virginia describes her zero-tolerance policy:

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.

Whereas riposte proved to be a method of dealing with maltreatment for the majority of the sample members, two respondents routinely use humour to defuse unpleasant situations. Kim explains:

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 ... 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!

Defiants may be angry or amusing, confrontational or defusing, but most of the respondents gave some examples of their defiance of insults and discrimination.

The Flamboyants

Julie is the only sample member who revelled 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', bright blue. She receives many comments, especially from young girls regarding her 'Barbie doll' like hair. To others, she is absolutely striking, and loves it. '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.

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

The Serenes

Three of the respondents conspicuously avoid confrontations and put-downs, and displayed considerable 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.

Tyrone, Julie and Matthew realised that they may very likely be the first person with albinism that a person in the general public may have encountered. Many people are often uncertain as how to interact with or react to people with albinism and the physical differences they possess. Julie explains how she manages adverse encounters with keen understanding and serenity:

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.

These respondents attributed their inner serenity to the acknowledgement that many people are not well versed in albinism. Even Matthew admits that he is not very knowledgeable about the genetics of albinism. Yet, he emphasised the necessity of explaining the facts about albinism, no matter how brief, to others who are genuinely interested and concerned.

The Activists

The misconceptions about albinism are widespread. Five of the participants are members of the National Organisation 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* that aims to 'open our eyes to the beauty of albinism', through photography (Guidotti, 1998, p. 65). Chris and Chantal are also actively involved in various organisations for people with impairments including the Montreal Association for the Blind, and the National Organisation for the Blind. Virginia has taken a different approach by creating an Internet website relating historical facts about people with albinism. She explains how she has been involved in increasing the awareness of 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.

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 impairment and unconventional appearance of people with albinism.

The Positivists

Verbal defence 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 in their lives; Julie, Tyrone, Chantal, Amy, Louise and Kim are the sample's most obvious Positivists. The Positivists feel that albinism is a significant and positive determinant of their uniqueness and authenticity. The Positivists and the Serenes share similar coping skills. 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 very frequent adversities they have endured, the Positivists have suffered the least because they are the most secure with themselves and with what they have to offer as people. The Positivists spoke at length about the importance of accepting and loving themselves as they are. They view their physical differences and impairment as simply a variation of the human population and recognise their uniqueness. In contrast to many of the other participants, they tackle adversities with an entirely positive attitude. Chantal explains, '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'.

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 deeply 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.

The Positivists were also forthright in explaining the importance of turning all obstacles into an opportunity to be sought. Self-acceptors have to be comfortable with their physical differences. They have accepted that aside from their impairment and differences, they lead productive, fruitful lives. Many have even chosen to assist others in need. As Julie says, 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'.

Discussion

People with albinism react to and resist the stigma of difference in different ways. They fight back at the derision and mockery they often encounter. 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 colours all aspects of their lives. The Serenes were keenly aware that albinism was a condition unknown to many because of its rarity. With this understanding, the respondents were tolerant of the many questions regarding albinism, and they responded with serenity and patience. They did not bother with anger or defiance. They did not hide or try to pass, as a rule. The Talkers found their families to be a source of endless support. It is with their family members that they were 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 Internalisers typically failed to assertively voice their opinions at the moment of confrontation. Instead, they internalised their pain and felt angry. For the Hiders, the derision was so overpowering that they felt the urgency to hide their impairment to escape prejudice. Both Internalisers and 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 coping mechanisms 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 approaches 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.

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 and the Defiants in their resistance against the stigma of difference. Both theoretical orientations are useful in explaining the various orientations of people with albinism.

The coping strategies adopted by people with albinism in this study are consistent with previous studies showing strategies developed by people with psoriasis, a chronic skin disease characterised by thick, red, scaly lesions which also carries with it the risk of social stigmatisation, physical impairment and psychological distress (Rapp *et al.*, 2001). In determining individual's efforts to cope with the social negative impact of psoriasis, Rapp *et al.* (2001) showed that patients with psoriasis indicated that they commonly used seven strategies to cope with others' negative reactions to their psoriasis. They were:

- 'I tell the person about psoriasis';
- 'I tell myself that some people are just plain mean';
- 'I keep my sores covered';
- 'I tell myself that most people just don't understand my problems';
- 'I avoid being around people';
- 'I tell the person that psoriasis isn't contagious'
- 'I tell myself that others can be insensitive' (p. 611).

These seven coping strategies are strikingly similar to those strategies developed by people with albinism shown in this study. The coping strategies that involve 'telling the person about psoriasis', 'telling oneself that some people are just plain mean' and 'telling oneself that others can be insensitive' are approaches that are similar to the ways the Positivists deal with social stigmatisation. Like people with psoriasis, the Positivists' unconditional acceptance of themselves allows them to explain their condition to others, while being fully understanding of reasons why others are often insensitive and unkind.

Concealment of unconventional physical appearance is also a common coping strategy for both people with psoriasis and albinism since their skin condition is visibly apparent to others. Individuals with psoriasis 'keep their sores covered' and 'avoid being around others'. The Hiders also adopt these coping mechanisms. To avoid the pain of oppression and to escape discrimination, they conceal themselves.

A display of inner serenity was another response to coping with social stigmati-

sation found in both studies. The Serenes engage in a similar coping strategy to people with psoriasis who 'tell the person that psoriasis isn't contagious' or tell themselves that 'some people just don't understand my problem'. The Serenes realise that they may very likely be the first person with albinism that a person in the general public may have encountered. Therefore, they are aware that some people do not understand the reasons behind their unconventional appearance. Like people with psoriasis, they willingly explain their condition to others, perhaps because it eases a primary concern others have and thereby reduces their social discomfort.

The results in the present study as well as in the study conducted by Rapp, *et al.* (2001) reveal that individuals with visibly apparent stigmatisable conditions commonly engage in particular coping strategies intended to avoid unpleasant social consequences and, in the worst cases, prejudice and discrimination.

Our research findings have led us 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 impairment. Our 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. They have positively identified with their differences and uniqueness, and refuse to view their condition as an impairment. Despite being frequently shunned by society, their positive attitude and strong will to accomplish their goals has allowed them to recognise 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 unique opportunities for achievement.

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