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Adaptation, positive learning, and methods of coping in women with congenital and acquired facial differences

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ADAPTATION, POSITIVE LEARNING, AND METHODS OF COPING

IN WOMEN WITH CONGENITAL AND ACQUIRED

FACIAL DIFFERENCES

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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ACKNOWLEDGEMENTS

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CHAPTER I

INTRODUCTION

The objective of this study was to explore and identify some of the positive and meaningful ways in which women with facial differences have dealt with the social difficulties they may have encountered in society. Women who are disfigured facially experience many disadvantaged social opportunities, as well as emotional and psychological distress (Benrud-Larson et al., 2003; Griffin & Langlois, 2006). Furthermore, public awareness and education about facial differences has not particularly been publicized or enforced in both the individual and institutional setting (Frances, 2000; Kent, 2000). This contributes to a lack of understanding or consciousness about this vulnerable population, and becomes problematic because it creates false assumptions and discriminatory acts. These negative beliefs may also then be internalized and reproduced in society, causing much personal distress as well as deprived social opportunities for those living with facial differences (Clarke, 1999; Stevenage & McKay, 1999). As a result, the empirical data collected during this research also aimed to help expand and add to the knowledge about women's adaptation, response, and resiliency to facial difference.

For the purpose of this research, the term 'facial difference' has been chosen to describe any participant who feels they have a disfigurement of the face (whether

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congenital or acquired later on in life during some childhood or adult event). Early

exploration on the accessibility of eligible subjects led me to speak to organization

leaders dedicated to helping this population, and it was through them that I learned the

term 'facial disfigurement' was rather pejorative. Therefore, the term facial difference

has instead been used to define my population.

Although previous research have been done in this area of study, they are

usually quantitative in nature do not as often examine the more subjective and personal

accounts of women living with facial differences. The current literature steadily reports

that the majority of individuals with facial differences have difficulty with social

interactions because they do not feel accepted or comfortable in public situations (Clarke,

1999; Kleve et al., 2002; Papdopoulos et al., 2000). Women in particular may have

additional challenges to encounter since so much emphasis is commonly placed in our

society on physical appearances and attractiveness (Benrud-Larson et al., 2003; Griffin &

Langlois, 2006). The literature also highlighted various findings related to school

experiences, employment opportunities, and social relationships (Stevenage & McKay,

1999; Frances, 2000; Kent, 2000), while the topic of intimacy was rarely if ever explored

in detail. In addition, the areas of positive learning, advantageous coping methods, and

resiliency in relation to having a facial difference were also not frequently covered in

research. Thus, this qualitative study along with a concentration on adaptation and

participant's strengths was conducted to further assist in learning more about the

experiences of women and facial differences.

Overall, this study examined adaptation and the positive strategies for coping

in 14 women with facial differences between the ages of 18-50 through direct telephone

interviews. Related questions in four areas including friendships/social relationships, school, employment, and intimacy (optional) were also explored in depth with open-ended questions from a structured interview guide. The information collected was used to identify both the negative and positive psychosocial consequences of living with a facial difference, and participants shared some personal insight as to what they have found helpful in dealing with discomforting situations and the journey towards self-acceptance. The aim was not to prove, but to further explore and advance the viewpoint that women with facial differences have dealt with numerous discriminatory experiences on a daily basis. How then can these women successfully adapt and overcome adversity or personal challenges to find safety and respite was what this study attempted to depict. Since this project intended to learn from the women themselves, the findings presented here would hopefully bring a different perspective on facial differences in order to help increase future awareness on this topic. It attempted to gather the subjective discriminatory experiences of these women to perhaps provide hope, support, and resources for other people who may be coping with a similar life experience.

CHAPTER II

LITERATURE REVIEW

Introduction

The purpose of this qualitative study is to explore and gain more knowledge and insight about the strengths, resiliency, and coping mechanisms women with facial differences have used to deal with discrimination based on appearances. Although a fair amount of research has been published in the area of facial differences, there are still relatively few studies done that focuses solely on the in-depth psychosocial issues that impact women. Due to limitations, the literature review will include an extensive but not exhaustive examination of research related to the topic of facial differences in women.

This chapter investigates and reviews the literature in several areas, beginning with the definition of facial difference, as it is an important term for this paper when referring to individuals of this population. Secondly, the magnitude of the face itself and the important role it plays in human interaction and development will be looked into among those who have a facial problem. The area of discrimination based on appearances will be explored, followed with some of the important psychosocial consequences for individuals in this population. Then, several specific but related social topics such as work, school, and intimacy are addressed. Finally, the topic of treatment options and adaptation as well as a summary of the literature review is incorporated. Since there is a

valuable amount of information related to men's experiences with a facial difference, this data is also being included as studies rarely only focus on female participants. In addition, few researchers have studied in great detail regarding the strengths and positive adaptations that individuals (especially women) with facial differences have made. Therefore, the literature will more frequently investigate one's social, environmental, and personal challenges. However, any areas relating to positive adaptation and healthy coping mechanisms will be included as available.

<u>Definition of Facial Difference</u>

It is not uncommon for individuals with visible differences to be referred to in pejorative or unfavorable terms. In fact, studies show that people who are considered more extreme in their appearances (e.g. disabled, disfigured) are often categorized for their deficits rather than strengths (Cole, 2000). For the purpose of this study, the term 'facial disfigurement' was originally used to describe individuals with any type of facial abnormality (whether from birth or acquired during some life event). For example, one could be born with a congenital facial disfigurement such as a cleft palate, while others could have acquired their disfigurement through an accident (e.g. fire and burns). However, my early exploration on the accessibility of eligible subjects led me to speak to organization leaders dedicated to helping this population, and it was through them that I learned the term 'facial disfigurement' was quite derogatory. Therefore, I felt it was politically relevant and respectful to replace the term 'disfigurement' with 'difference' in regards to this population. Although all the literature and research refers to this population as 'facially disfigured,' I will not be using this term. Instead, what is relevant to this paper and the purpose of using facial difference is the focus on positive strengths,

adaptations, and coping mechanisms that women have used to help navigate their social and personal world.

The Importance of the Face

In order to better understand the uniqueness of the face, it's functions, and the role it plays in society and our inner selves, research suggests that we must first look into the experiences of individuals with facial differences (Cole, 2000; Callahan, 2004). This is because the face is so critical in terms of acting as a visible source of expression for one's inner self and personality (Callahan, 2004). The face not only embodies a large part of our presentation to the world, it is how a person is predominately recognized and later recalled through mental images (Callahan, 2004). In contrast to other body parts (e.g. limbs, torso), the face is capable of extremely intricate and complex fine muscle movements that express moods and emotions (of all intensity), perceptions, self-awareness/reflection, and interactions of all sorts (Van Loey & Van Son, 2003). In previous studies with head and neck cancer patients who had undergone facial changes, many reported a loss of sense of self and negative changes in self-image (Moadel et al., 1998), and studies among patients with reduced facial mobility due to Parkinson's disease also reported a compromised sense of self-worth and limited attractiveness (Cole, 2000). Therefore, some data is indicating that having a facial difference can be extremely challenging, as the face plays the most crucial role in defining ourselves to friends, family, and strangers. The face can also directly affect our interpersonal interactions and may correlate with our social successes or social failures, thus impacting our self-esteem and self-worth (Cole, 2000).

Other research has stressed the importance of the face and it's symbolic value as being cultural and socially defined (Hahn, 1987; Elks, 1990). Dion, Bersheild and Walster's (1972) *What is Beautiful is Good* is an old but important article outlining the existence of an attractiveness bias in society. People who are seen as physically attractive are also seen as socially more desirable, in control, and have other positive qualities attributed to them (e.g. higher intelligence, hold more prestigious jobs). Currently, the attractiveness bias is still highly reinforced in our culture (Elks, 1990), and certain physical characteristics are consistently regarded as positive and desirable while other different characteristics are associated with more negative connotations. These differences may include but are not limited to race, gender, disability, and disfigurement. The media also plays a big role in shaping people's attitudes towards personal appearance, which works against those with visible disabilities and devalues facial differences (Cole, 2000; Hahn, 1987). Hence, people with facial differences may experience facial prejudice (Cole, 2000), or discrimination based on appearance in multiple areas of society.

<center>Discrimination of Women with Facial Differences</center>

The literature on facial differences indicates that the majority of individuals in this population have difficulty with social interactions because they do not feel accepted or comfortable in public situations (Clarke, 1999; Kleve et al., 2002; Papdopoulos et al., 2000). This mainly occurs because one is likely to feel anxious and fearful of what other people's reactions or responses to their facial difference may be, particularly in social spaces where appearance is more valued and emphasized (Hawkesworth, 2001; Papdopoulos et al., 2000). It is especially difficult for women with facial abnormalities

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because Western ideals have put so much emphasis on appearance and attractiveness that women are under constant scrutiny when it comes to their looks (Benrud-Larson et al., 2003; Griffin & Langlois, 2006). These socially constructed ideals associated with women's attractiveness and the negativity bias can be especially problematic in our society. Women with facial differences are at an extreme disadvantage (compared to non-disfigured individuals) in numerous situations including personal, professional, social, psychological, and political settings. Furthermore, treatment, awareness, and understanding of underprivileged women's issues have often been ignored or underrepresented in our society, so policies and programs regarding discrimination based on facial differences have not been sufficiently addressed (Griffin & Langlois, 2006; Hawkesworth, 2001). It is important to consider that women with facial differences may experience many forms of discrimination on a daily basis. Since there is a significant lack of education and awareness to the general public about the conduct and interpersonal aspects towards people with facial differences (Kent, 2000; Frances, 2000), these problems may remain unresolved and women will continue to be subjected to unfair treatment.

The stigmatization of facially different individuals and the internalization of that stigma remains a common theme in people with facial differences (Lawrence et al., 2006; Newell & Marks, 2000). For example, research has found that enacted stigma and felt stigma seemed to be common (Kent & Keohane, 2001), which also related to increased social anxiety and the development of phobias (Newell & Marks, 2000). This is not surprising considering the consistent unpleasant daily encounters that facially different people come across, including staring, derogatory remarks, avoidance, fear, and disgust.

Particularly in today's appearance conscious society, acts of discrimination against those who are visibly different may be more covert than in the past. It is important to consider that people amongst this population already feel vulnerable and are sensitive to other's reactions, and this combination along with a negative self-image and lack of confidence may lead to feelings of shame, anger, and hopelessness. Individuals with facial differences also suffer from low self-esteem, self-consciousness, and a feeling of worthlessness (Fauerbach et al., 2002; Papdopoulos et al., 2000).

Another problem with discrimination of people with facial differences is that there is a general lack of awareness and advocacy around this topic. For example, there are relatively few role models, media personnel, and public figures with facial differences that could potentially bring more awareness to the community (Clarke, 1999). In most cases, unless an individual or organization comes into direct contact with a person with a facial difference, then there is little responsiveness and motivation to address and enhance one's understanding of the issue. This leads me to conclude that the majority of people receiving any types of intervention are those with a facial difference themselves and their close network of friends and family. However, this not only leaves the problem of discrimination wide open and unexplored for people without some type of facial difference, it also minimizes and hides the expression of true feelings and experiences that this underrepresented population may endure.

The Psycho-Social Impact of Having a Facial Difference

Based on early observation and study, McGregor (1953) was one of the first researchers to have perhaps best predicted that facially different individuals discovered early on that they were socially inferior, and were assigned a marginal/minority status in

society. The opportunities that were made available to the general public may often be denied for this population, and relationships/friendships as well as a variety of cultural activities were likely to be affected or altered in some manner.

In the past twenty years, interest in the psychosocial consequences from congenital and acquired facial differences has increased and become more publicized in research (Callahan, 2004; Dropkin et al., 2003, Rumsey & Partridge, 1994). It is disheartening to note that earlier hospital patients whom were treated for disfiguring conditions, such as burns and skin diseases, were not systematically or routinely screened for risk of psychological distress (Martin & Newell, 2005). Similarly, patients recovering from reconstructive surgery were given little resources to help cope with adjustment or treatment options for managing psychological distress (Van Loey & Van Son, 2003). As a result, many people with facial differences, especially women, suffered from low self-esteem, poor body image, extreme self-consciousness, anxiety, embarrassment, and internalized negative beliefs (Dropkin et al., 2003). These beliefs then may be expressed through behaviors such as an avoidance of social interaction and difficulty meeting new people and making friends (Dropkin et al., 2003; Leoy & Son, 2003; Rumsey & Partridge, 1994). In addition, it has been observed that women with facial differences are likely to be at an elevated risk for psychological disturbance, specifically a higher level of anxiety and depression (Newell, 2000). Furthermore, this population may also be at high risk of psychological morbidity in terms of social phobia due to the constant negative evaluations of daily encounters in one's environment (Newell & Clarke, 2000).

One of the main detrimental effects of social phobia and other social problems reported by individuals with facial differences is isolation and an inability to regain social

currency due to the fear of rejection (Callahan, 2004; Cole, 2000; Partridge, 1990). Many women with facial differences report they are reluctant to go out in public due to the staring and rude remarks they may receive (Elks, 1990). Other common responses include being avoided in public areas, blatant staring, startled reactions, rude remarks, and uncomfortable personal questions (Elks, 1990; Van Loey & Van Son, 2003). Empirical evidence has documented that participant's perceptions of avoidance towards them based on their appearance is likely to be correct, however, other responses besides avoidance have not always been accurately perceived by people with facial differences (Van Loey & Van Son, 2003). This is significant because individuals with facial differences may perceive social interactions differently and in a more distrustful manner than intended by others. Once again, these cognitive distortions are internalized and accumulate over time, making it even more difficult to socialize in a healthy manner. Additionally, these negative thoughts may lead an individual to further isolation, and the loss of social networks as well as a decrease in self-confidence and self-esteem. Therefore, it is important to find ways to change negative thought patterns and perceptions before they become too severe or affect a person's ability to function and live a normal life.

In the real world, confidence may be built by the ability to trust that others will validate our self and help enhance our self-esteem (Cole, 2000). However, the development of confidence is really difficult for women with facial differences because they are often perceived as unattractive, boring, unsociable, and withdrawn (Cole, 2000). Soon, these women start to believe that they do possess all these negative attributes and it may then become a self-fulfilling prophecy (Cole, 2000). This leads to shame and further

isolation, and possibly the development of social phobia or depression along with a high level of anxiety (Newell & Clarke, 2000). Cole (2000) uses the acronym SCARED to discuss the complex mixture of feelings, thoughts, and behaviors that people with facial differences may experience. SCARED decently summarizes the experiences of individuals with facial differences and stands for self-consciousness, conspicuousness, anxiousness, rejection, embarrassment, and difference.

Research has supported the theory that people with visible physical differences tend to have difficulty interacting and relating to other people in fear of rejection, shame, and embarrassment (Callahan, 2004; Rumsey & Partridge, 1994). Unfortunately, the negative consequences of having a facial difference not only affect a person's psychological well being, they also can impact critical areas such as work, school, and intimacy.

<u>Work Setting</u>

Research has often shown the advantages of physical attractiveness in areas like work, as these individuals are not only more likely to be hired, they are also seen as having higher social skills and a greater likelihood for success in life (Elks, 1990; Stevenage & McKay, 1999). It was only in the past few years that research was done about the possible disadvantages of facial differences in the institutional setting, specifically the work environment (Stevenage & McKay, 1999). The conclusions were quite disturbing, with an overwhelming negative bias towards facially different individuals in the recruitment setting. Results indicated that recruiters were much less likely to hire a facially different applicant (port-wine stain) than an applicant with a physical disability (wheelchair). In addition, applicants with both a physical disability

and a facial difference (having both a port-wine stain and being in a wheelchair) were least likely to be hired (Stevenage & McKay, 1999). There was also a significant marked negative perception of applicants with facial differences in terms of both personal qualities and job skills that were not perceived with disabled clients (Stevenage & McKay, 1999). Obviously, these findings contradict the law against discrimination in policies regarding hiring (America with Disabilities Act, 1990), but little is currently being done to address the issue.

 The interesting aspect about Stevenage & McKay's study (1999) was that most of the participants with facial differences perceived not just the interview portion to be biased, but the whole recruitment process was seen as unpleasant. For example, this included not being greeted by the receptionist, discomfort while sitting in the waiting room, and encountering other workers when leaving the building. This may show that even indirect interactions in certain social situations may strongly impact an individual's perceptions and experiences with others if they have a facial difference. It is important to gain further insight about a person's discernment of discriminatory experiences, no matter how slight or concealed they may be for the general population to recognize. Also, gender differences were not examined in this study done by Stevenage & McKay (1999), so women's experiences regarding work and recruitment have not yet sufficiently been explored in great detail.

<div align="center">Intimacy</div>

 Current research on facial differences has also rarely addressed the issue of sexual intimacy and relationships (Hawkesworth, 2001). There is little empirical evidence and research published around this issue, although suspicions about sexual dysfunction

have been among health professionals for quite some time (Van Loey & Van Son, 2003). This may be due to the researcher's own biases around disfigurement and intimacy, or it may be considered too private or uncomfortable of a topic to study. Also, it is possible that patients avoid complaining about intimacy related problems to their health professionals due to shyness and embarrassment (Van Loey & Van Son, 2003). I speculate that this is more prevalent amongst women, as feelings and attitudes towards sexuality and sexual expression may still be viewed as immoral and taboo (Griffin & Langlois, 2006; Hawkesworth, 2001).

However, I do feel the lack of awareness about facial differences in general may partially be responsible for creating and maintaining negative ideas and perceptions around intimacy with this population. Similar to misconceptions about people with physical disabilities, women with facial differences are often viewed as incapable of having intimate relationships or being physically desirable and attractive (Griffin & Langlois, 2006; Hawkesworth, 2001). Some of the devastating effects of these discriminatory beliefs include the negative impact it has on women's self-esteem and self-image, as well as a sense of hopelessness about being able to find a partner who is willing to accept their facial difference (MacGregor, 1979). More so, these internalized views also impacts a person's willingness to interact with others in social situations, and relationships in general can be extremely difficult and a cause of distress (Bernad-Larson et al., 2003; Lawrence et al., 2006).

In one study with head and neck burn patients, it was reported that disfiguring scars may affect sexuality in that a negative alteration in appearance may impact one's body image and self-esteem, both of which are important factors in sexual life (Van Loey

& Van Son, 2003). It was also found that sexual satisfaction among women was affected by physical dysfunction as well as body image (Van Loey & Van Son, 2003). Brooking & Bull (1984) did a very early and interesting study on how marriage affected whether a disfigured person would be considered physically attractive or not. Participants were asked to evaluate a photo of a couple where one spouse had a facial difference while the other did not. The fascinating results showed that when a spouse with a facial difference was associated through marriage with someone without any facial differences, they were not perceived in a negative manner. These results contradict earlier studies, which have consistently supported the theory that "what is beautiful is good" (Dion et al., 1972). For example, Bar-Tal & Saxe (1976) had students evaluate pictures of married couples who were either similar or dissimilar in attractiveness. The results indicated a significant gender bias, in that women were evaluated independently while men were evaluated based on their relation to their wife's attractiveness (Brooking & Bull, 1984; Bar-Tal & Sax, 1976). Therefore, unattractive males married to attractive females were evaluated highly on many characteristics but not vice versa. Likewise, one may suggest that in Brooking and Bull's study (1983), perceptions of the facially different spouse may not have been as negatively influenced due to a belief that this person has achieved and overcome tremendous adversity and prejudice in society to be in this relationship. In fact, it is likely assumed that this individual has incredible social skills and achievement because he/she is married to a person without a facial difference. However, this theory is quite uncomplimentary and focuses on the assumption that facially different individuals are somehow only considered worthy of respect and love if they can manage to find a spouse that may overlook their physical appearance.

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However, the conflicting results from both studies are important as they may demonstrate how gender may affect a relationship if one partner has a facial difference. In addition, research about relationships and intimacy may help broaden our understanding of ways to help treat and development interventions to assist individuals regarding this sensitive but important topic. Currently, availability and knowledge regarding sexual help for individuals with facial differences is quite limited, and only includes sexual health promotion and sexual counseling to help reduce sexual problems.

Treatment

One area that has created interest among researchers is using cognitive behavioral therapy as the main form of treatment to help individuals cope with their facial differences and handle general social situations in a more positive manner (Clarke, 1999; Kleve et al., 2002). Treatment strongly recommends including social skills training and psycho-education as well as group work to help people gradually adapt and live with their different faces (Partridge, 1994; Robinson et al., 1996). One of the earliest programs designed to offer direct help regarding the psychosocial aspects of living with a visible difference of the face was Changing Faces (Partridge, 1994). This non-profit organization has been very influential in the field of facial difference awareness and treatment, as similar non-profit programs such as AboutFace and Outlook have developed later on and seemed strongly influenced by Changing Faces (Clarke, 1999; Kent & Keohane, 2001; Kleve et al., 2002). James Partridge, an undergraduate at Oxford who was badly burned in a car crash, started Changing Faces in 1994. Partridge survived the traumatic crash and as he began the slow and tortuous road towards recovery, he realized that although his physical health was well looked after, he received little advice or psychological

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support during his aftercare. His face was not only badly scared due to multiple plastic surgeries and skin grafts, he had also lost some mobility and function of his mouth and nose area. Partridge felt that one of the most challenging aspects of living with a facial difference was regaining social entry into the world, and knowing how to handle the uncomfortable daily encounters with people in public. He wrote the book *Changing Faces* (1990; 1994), as a tool to help people come to terms with their changed face and how to restart their lives.

In 1994, Nichola Rumsey (a health psychologist) and Partridge worked together professionally to create Changing Faces to help those with facial problems. They also introduced the idea that having social skills (to help cope) was the most important aspect of recovery from social phobia (Partridge, 1997; Robinson et al., 1996). Like many current treatment options, Rumsey and Partridge first introduced workshops and individual counseling to help facially different individuals in need of support and distress management. For example, it was encouraged during workshops that members focused on their bad experiences, talk about them in front of strangers in a new place away from home, and address their fears of rejection, discomfort, and anxiety in public (Partridge, 1994; Robinson et al., 1996). Once people's protective pretenses were stripped away, Changing Faces helped individuals regain social currency, including ideas about taking the initiative, gaining control, and meeting new people. The acronym often used during workshops was REACH OUT, as it stood for reassurance, energy, assertiveness, courage, humor, otherness, understanding, and tolerance (Cole, 2000; Partridge, 1994). Facially different individuals needed reassurance that they were not passive victims, and could regain a sense of control and strength in their social and personal environment. Other

important social skills strategies, such as demonstrating ways to begin and end a conversation, and building and maintaining relationships with new/old people were also practiced and reinforced (Partridge, 1994). Since dealing with embarrassing and uncomfortable social situations in public was also often encountered on a daily basis, organizations like Changing Faces focused on exploring and rehearsing specific coping strategies for handling such instances with humor and confidence (Partridge, 1994; Robinson et al., 1996). Changing Faces, AboutFace, and Outlook all currently use workshops, cognitive behavioral therapy, and psychomotor techniques to enhance self-esteem, self-confidence, and body image.

In general, workshops that include social skills training and strategies for coping have been shown to reduce social anxiety, as well as self-help leaflets and groups (Clarke, 1999; Kent & Keohane, 2001; Partridge, 1994; Van Loey & Van Son, 2003). Particularly, psycho-educational groups have been successful at reaching out to isolated or fearful people who have become this way due to their changed appearance (Callahan, 2004). In addition, resources for children about bullying and self-advocacy have also served beneficial in the school setting (Cole, 2000; Frances, 2000).

<u>Adaptation</u>

The actual adjustment process and responsiveness to treatment may be affected by many variables, including individual coping style, social support, and personality traits both pre and post injury (Van Loey & Van Son, 2003). Studies have shown that high levels of emotion-focused coping and low levels of acceptance coping correlate with PTSD symptoms and general emotional distress (Callahan, 2004; Van Loey & Van Son, 2003). Avoidance and having a lower quality of life are also associated with emotion-

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focused coping (Van Loey & Van Son, 2003). Interestingly, it was found that women used emotion-focused coping more often than men, and successful coping was found to be positively related to the personality dimensions of extraversion, optimism, self-mastery, and hope (Van Loey & Van Son, 2003). It was found that good problem solving skills and the ability to seek emotional support increased one's quality of life, as did other problem oriented coping styles (Callahan, 2004; Van Loey & Van Son, 20003). Critical indicators of recovery according to the Disfigurement/Dysfunction Scale (Dropkin et al., 1983) indicates that self care and interaction with family and friends are important for healing and the level of adjustment, adaptation, or maladjustment in patients (Callahan, 2004).

In terms of social support as an important part of treatment, Patterson et al (2003) found that social support was positively related to self-esteem, positive body image, and life satisfaction among patients with severe facial burns. Cash & Grant (1995) developed a cognitive behavioral model to help with body image problems that may be applied to individuals with facial differences. The model helped change body image schemas, and when tested out among patients with Vitiligo (a condition that causes loss of pigmentation in skin), results indicated significant improvements in one's quality of life, self-esteem, body image, and negative thoughts (Cash & Grant, 1995).

Therapists who work with facially different individuals should examine the client's perceptions, areas of struggle, coping strengths, and problem solving abilities (Callahan 2004). Furthermore, therapists must be willing to listen and effectively manage their own countertransference, as clients have often been avoided or shunned in the past and may currently be cautious and distrustful of others due to their appearance and

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presentation (Callahan, 2004; Cole, 2001; Van Loey & Van Son, 2003). Some research suggests that the key to adaptation and development of helpful strategies is empowerment, and the confrontation of one's worst fears and gradually dealing with them with through exposure to the fearful situations paired with social and emotional support (Callahan, 2004). This method may also help clients develop empathy for others who may be experiencing similar situations, and creates a mindset that is better able to relate and communicate.

Another helpful but much needed area of research and advocacy is community interventions for people with facial differences. It has been suspected that the population who mainly utilizes services (e.g. AboutFace and Changing Faces) are families of individuals with facial differences, those with facial differences themselves, and certain professionals (Clarke, 1999; Kleve et al., 2002). It is significant to also recognize that school curriculums and educational awareness programs do not usually consist of addressing or providing adequate support for students with facial differences (Frances, 2000). In fact, programs such as Changing Faces School Service found that the teachers and staff members knew relatively little or no information about how to effectively work with a pupil with a facial difference. Yet, programs such as Changing Faces School Service are not considered a mandatory part of training in most school systems (Frances, 2000). The Changing Faces's school re-entry program aimed at altering negative pre-existing attitudes and knowledge regarding facial differences was shown to be beneficial and of interest to school staff members when used (Frances, 2000). Consequently, these programs along with additional educational resources should be seriously considered and implemented in all school systems to help both children and adults.

Although it is critical to realize that support groups and psychoeducational programs such as Changing Faces, About Face, and Outlook have all been shown to be effective in helping people with facial differences (Clarke, 1999; Kent & Keohane, 2001; Kleve et al., 2002), it is still possible that not enough information is known about the subjective experiences and goals pertaining to individuals with facial problems. Researchers have mainly focused on quantitative studies regarding anxiety, social withdrawal, self-esteem, self-image, work-related difficulties, and the outcome of treatment plans (Clarke, 1999; Kleve et al., 2002; Lawrence et al., 2006; Newell & Marks, 2000; Papdopoulos et al., 2000). Although these studies provide valuable information and important contributions in better helping patients with facial differences, they lack the in-depth exploration and detailed descriptions to further understand the experiences of women with facial differences. The majority of these designs measure a patient's experience using some type of survey or scale (e.g. Fear Questionnaire Problem) and based on these answers, results are drawn, conclusions are made, and future areas of research are recommended or implemented. For example, the 12 items General Health Questionnaire (GHQ-12) was said to be effective in measuring psychological distress in all clinical populations. However, studies have shown that the questionnaire was not a reliable unitary measure of psychological distress with individuals with facial differences (Martin & Newell, 2005). Even though it is important to recognize that quantitative studies have paved the way for future research and awareness on facial differences, it might not be the most all-encompassing method of research as each participant's experience may be distinct. Conclusions that are drawn from quantitative studies are not

specific to individual opinions or evaluations; instead, they are more generalized and give less of an in depth personal understanding of people's experiences.

Also, surveys or scales have a tendency of limiting the fluidity in responses, perhaps leading to important information or insight that may be missed. The research that has previously been done does not pay particular attention to gender differences, and identifying the more specific experiences of women would be insightful and useful when comparing possible future qualitative studies with men. Qualitative results may also be helpful in designing more gender specific treatment programs that are better matched to a particular population's needs (in this case, women with facial differences).

Summary of Literature Review

This current papers aims to explore and depict to the best of my ability adult women's strengths, adaptations, and positive coping methods to manage discrimination and social difficulties due to a facial difference. A qualitative study was conducted to further investigate and advance the viewpoint that women with facial differences have to deal with a range of discriminatory experiences on a daily basis (specifically in areas such as social relationships, work, school, and intimacy). As a result, when and how these women can successfully find safety, respite, and resources for coping despite adversity and personal challenges is what is portrayed in this study. Once again, the purpose is not to prove but rather broaden and add to the knowledge already known about women's adaptation, response, and resiliency to facial difference.

In this literature review, certain specific social and interpersonal areas of life are addressed and discussed including social relationships, work, school, and intimacy. The psychosocial consequences have been shown to have a significant impact on the

behaviors and self-image/self-esteem of women with facial differences, and are related to the treatment progress and patterns of adaptation. Women with facial differences experience many disadvantaged social opportunities, as well as emotional and psychological distress. In addition, public awareness and education about facial differences is not particularly publicized or enforced, and this lack of consciousness or understanding becomes problematic because it creates false assumptions, internalized negative beliefs, and discriminatory acts.

Overall, this vulnerable population is highly underrepresented yet remarkably discriminated against in the public domain. It would be beneficial to have additional involvement from the general community to be more motivated and advocate for awareness and positive changes. Before public advocacy and outreach might begin, I believe it is important to first understand in greater depth how women with facial differences feel about themselves and what positive adaptations and coping mechanisms have been helpful. Since this study seeks to learn from the women themselves, the qualitative nature of my research may bring a different dimension and perspective to the topic of facial difference. I sincerely hope that the subjective information gathered from these women will be used to provide support, assistance, and resources for other people who may be coping with a similar life experience.

CHAPTER III

METHODOLOGY

The purpose of this project was to explore and depict the positive and helpful ways in which women with facial differences have dealt with the social difficulties they had encountered in society. This study aimed to further identify and gain additional knowledge and insight about the strengths, resiliency, and coping mechanisms that women with facial differences have used to deal with discrimination based on appearances. Particular emphasis was focused on providing participants with the opportunity to contribute useful strategies that may benefit or support other people in similar circumstances.

Since most studies about facial differences had been quantitative in nature and usually concentrated on issues such as body image, anxiety, and evaluating the effectiveness of certain treatment plans, a qualitative method with an exploratory approach was used for this study. Fourteen participants were interviewed in-depth through direct telephone contact to examine the more subjective and personal accounts of their experiences of living with a facial difference. A structured interview guide that included four main open-ended questions and one optional question was used. Findings were then analyzed qualitatively through selective transcription and thematic analysis. After data collection and analysis were completed, one participant was randomly selected

to win a 20-dollar gift certificate to Borders Book Store and received the gift card by mail.

<center>The Characteristics of the Participants</center>

The goal was to have a maximum of 15 women (a minimum of 12) between the ages of 18-50 to voluntarily participate for this study. Participants needed to have either a congenital facial difference or an acquired facial difference because of some childhood or adult event. The women must also either be in school (full time, part-time), or be employed currently or have been employed during some point in their lives (self employed is ok). The study initially aimed to sample only women with acquired facial differences, but due to a significant lack of participants available in this specific population, it was necessary to broaden sampling to women who were also born with facial differences. Since the degree of severity of the facial difference and how one felt about their appearance could be quite subjective, all women with any type of facial difference that may or may not have already been altered due to surgery were eligible for screening. Participants could also be from any racial or ethnic group, as long as they were able to speak English because no translator was provided.

<center>Recruiting a Sample</center>

Participants were recruited based on availability and snowball sampling. In addition, the researcher had the opportunity of contacting the director of AboutFace, a national non-profit organization dedicated to helping individuals and families with facial differences (this agency and their contact information was found through Internet research on facial differences). The director then graciously volunteered to help recruit participants that had been associated with the agency who may also possibly be interested

in being a part of this study. Other support-based websites were also contacted in case

more participants were needed.

However, AboutFace was one of the biggest and most well-known online

resources for individuals with facial differences, so their support and assistance was used

first to help recruit participants. The director offered to make the initial contact with any

possible participants who may be interested, since she already knew most of them and

had established a relationship. A copy of the recruitment form (Appendix D) was first

submitted to the director who then sent it through e-mail to women she considered would

be potentially eligible participants. The original plan was to utilize direct-phone calls to

contact possible participants, but e-mail was used instead because it turned out to be a

much quicker and more convenient method of recruitment for the director. The

recruitment form included a brief introductory paragraph about the researcher and the

purpose/nature of the study, as well as my contact e-mail and phone number. It also

inquired whether it would be all right for the researcher to contact any potential

participants soon by telephone, and if so, to provide the director with written permission

through e-mail.

Once participants expressed an interest to the director and gave her permission

for me to contact them, the following plan of action occurred to help the recruitment

process go as smoothly and promptly as possible. A telephone call was made or e-mail

sent to contact potential participants to help further explore the nature of their

participation. It was soon discovered that using e-mail rather than telephone was a much

easier and more efficient way of contact, as participants were located all over the country

and were often not home when called. All women were then screened to see if they fit

the appropriate criteria based on age, presence of facial difference, and whether they are/were in school or work at some point in their lives.

After participants communicated interest following the initial contact and screening process (and fit the criteria), they were provided with the Informed Consent (Appendix B) and a self-stamped envelope through mailing. Two copies of the Informed Consent were mailed so participants could keep one copy for their own records, and the second copy would be returned back to the researcher. Once participants returned a copy of their Informed Consent, the participant and researcher decided on a set time and date that was most convenient for the telephone interview to take place. The researcher then called the participant to conduct the interview as scheduled.

During the recruitment and screening process, a significant effort was made to include a diverse range of participants based on race and nature of facial difference. However, due to the limited availability and small sample size, it was very difficult to fully accomplish this goal. As a result, the vast majority of participants were women with congenital facial differences, in particular participants with a cleft lip and palate.

A total of 19 women were contacted for possible participation in this study. Of the 19 women, 2 mailed back their Informed Consents but did not respond to any further phone calls. One woman had to withdraw for personal reasons, and another woman did not reply within the limited time frame for participation. Therefore, the final sample consisted of 14 participants with facial differences.

<u>Participants</u>

This research study included 14 women participants, 13 had a congenial facial differences and one had an acquired facial difference. The average age of participants

was 34.6 years old (range 25-46 years). The participants (n=11) mainly all identified as Caucasian, while one participant (n=1) identified as Black/Puerto Rican, another (n=1) as Caucasian/Jewish, and another (n=1) as Latino/Caucasian. Of the participants (n=13) with congenital facial differences, the nature of their facial difference varied from cleft lip and palate (n=9), Apert syndrome (n=1), Freeman Sheldon syndrome (n=1), Fibrous Dysplasia (n=1), and Robinow syndrome (n=1). The participant (n=1) with an acquired facial difference had sustained injuries to her nose, mouth, and chin area due to a biking accident when she was 13 years old.

Participants also held various occupations including Health-care worker (n=3), Homemaker (n=2), School employed (n=2), Non-profit (n=2), Advertising/Marketing (n=2), Engineering (n=1), Book keeping (n=1), and Customer care representative (n=1).

Data Collection

The Human Subjects Review Board of Smith College School for Social Work approved the design and implementation of this study (see Appendix A). The Informed Consent letter summarized the nature and purpose of this study and outlined participation details, as well as any possible benefits and risks involved. Participants were first asked a small set of demographic questions including age, race/ethnicity, nature of their facial difference, how many years the participant had lived with the facial difference (this question would not apply to participants with congenital facial differences), and occupation.

A structured interview guide (Appendix C) that listed in outline form the five main topics and issues that would be included throughout the interview process was used to collect data. The same interview guide was applied to each participant, as there was

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enough flexibility to explore and adapt to discussions depending on the content of the participant's responses. The interview guide was also used to help better organize and cover the same basic material with each participant, and help reduce biases and inconsistencies. A final pre-test and mock trail of the interview guide with three Smith students was used to help critique and prepare for the actual interview process. The main questions for each of the five subcategories were open-ended, and probes were used when appropriate to help further explore, clarify, or converse during the majority of the interview.

Questions for the interview had been limited to five, to account for the possibility of long and detailed responses in combination with time restraints. Participants answered three general questions that involved separate but interrelated aspects of adaptation from discriminatory experiences, and one question that focused on the overall strengths and adaptive pathways (if any) that have developed from this experience. The last question on intimacy was mentioned at the end of the interview and remained optional due to the private nature of the topic. Participants were told that they were not obligated to answer any questions they did not feel comfortable doing so, and their responses would not have an effect on their value of participation

The direct telephone interviews usually lasted somewhere between 30 to 70 minutes, depending on how much information was shared and discussed. Participants were always given the option of exploring each question until they were finished, and time was relatively flexible during these interviews. Notes were also taken by hand as the interview was tape-recorded to help organize and analyze the data later on.

Data Analysis

Due to the very personal nature of this study, each participant was assigned a number to help keep track of their data while all identifying information was erased or disguised during analysis and note taking. Since interviews were tape-recorded and provided enough sufficient direct evidence for coding, routine transcription was not used in every interview. Instead, selective transcription was done for clarification, review of content, and analysis on a needs basis.

After each tape-recorded interview, the data and notes were then carefully read all the way through and thematically analyzed. Since the interviews all followed structured guidelines, salient themes and characteristics that portrayed the range of experiences were identified while themes and sub themes were pulled together. These themes were then compared, contrasted, and similarities or differences were noted as well as significant patterns and outliers. Any ideas or concepts that were not captured or unexpectedly produced from interviews were also included in the analysis. Finally, quotes from selective transcription were used to further identify and support these impressionist judgments based on the data collected.

CHAPTER IV

FINDINGS

The following chapter incorporates the findings of my study through 14 phone interviews among adult women with facial differences. It was explained to each participant during the beginning of the interview that the focus of my research was to comprehend the positive and advantageous ways in which they have coped, adapted, and understood their strengths through experience. During the beginning of each phone interview conversation, the term 'facial difference' was defined as any visible difference of the face (whether congenital or acquired through some childhood or adult life event). In addition, participants were also told that they would be asked four main open-ended questions with one optional question at the end. The interviews were recorded and conducted in a casual manner, while participants were encouraged to ask questions or take a short break whenever needed.

The interview guide used was structured to include four main categories and one optional category (at the end of the interview) due to the private nature of the question. The outline of the interview guide focused specifically on identifying information, friendships/social experiences, employment/school experiences, positive learning and methods of coping, and intimacy (optional). Participants were asked open-ended questions as often as possible for each category, while prompts were mainly used to help further elaborate, discuss, guide, or clarify one's response.

The findings collected from these interviews will be discussed according to the order in which the questions were presented on the interview guide. Therefore, this chapter will begin with identifying information, followed by friendships/social experiences, employment, school, positive learning and methods of coping, and finally intimacy.

<u>Identifying Information</u>

<u>Participants</u>

As previously noted, 14 women (n=14) between the ages of 18-50 participated in this study. The average age of participants was 34.6 years old (range 25 to 46 years). The vast majority of women (n=11) identified as Caucasian, while one woman (n=1) identified as Caucasian/Jewish, another woman (n=1) as Black/Puerto Rican, and finally one woman (n=1) identified as Latino/Caucasian. According to the nature of the participant's facial difference, it is significant to note that 13 women had congenital facial difference (n=13) while only one woman had an acquired facial difference (n=1).

Within the 13 women with congenital facial differences, an overwhelmingly large portion of participants had cleft palates (n=9). The remaining number of participants with other congenital facial differences included the following: Apert syndrome (n=1), Freeman-Sheldon syndrome (n=1), Fibrous Dysplasia (n=1), and Robinow syndrome (n=1). The only participant whose facial difference had been acquired was involved a biking incident, as she sustained unsightly injuries to her nose, mouth, and chin area. Since she had an acquired facial difference, the question regarding the years she had lived with this facial difference was applicable. The answer to that was 31 years, as the accident happened when she was 15.

Finally, participants were asked to identify their occupation, as they would later be asked more regarding their employment experiences. The range of occupations was vast, as participants were involved in numerous different fields of work. Therefore, employment has been organized into several categories that may best classify each job description: Health-care worker (n=3), Homemaker (n=2), School employed (n=2), Non-profit (n=2), Advertising/Marketing (n=2), Engineering (n=1), Book keeping (n=1), and Customer care representative (n=1). All participants were also currently living in the United States.

<center>Friendships/Social Experiences</center>

Participants for this second question were mainly asked to discuss their experiences with social relationships including friends, family, community, and new people/places. Once again, the prompting questions were open-ended and additional questions were asked depending on the direction and clarity of each response. Participants always had the option of providing as much or as little information as they were comfortable with. In this section, Participants were invited to share their perspectives and understanding of their experiences around family and friends. Also, participants were asked to consider and talk about a social situation that they would likely feel most comfortable in, and a social situation that would present as most challenging.

<u>Family</u>

In response to the first part of the question regarding family, a significant amount of participants felt that close family (and friends) were a vital and important aspect of their social support system. The general consensus regarding family seemed to be that from an early age, caregivers were sensitive and receptive to not treating them as

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"handicap" individuals. In other words, their immediate families were respectful and encouraged them to pursue their interests without feeling hindered by their facial difference. Furthermore, most participants felt that their family provided a steady source of safety, comfort, and happiness that contributed to their current outlook on life. Therefore, it was shown that those who felt they received adequate affection, empathy, and care from their families seemed to feel less introverted and more positive about new social experiences and being around other people.

Although the general responses about family seemed to mainly center on what was previously noted by participants, there were a few women whom did not feel their families played such a positive role in helping them cope with their facial difference. Some participants remembered feeling "like I was the only one who looked like this" or "my parents tried to fix me." It was primarily understood by participants that perhaps their families were not completely comfortable or ready to help them deal with the difficult and challenging aspects of living with a facial difference. Family members may often be "over-protective because there were no other children or adults with facial differences in my community." Even though many women recalled that their families were trying to be helpful and supportive, they still perceived themselves as being different and would often feel insecure and shy around others.

One unexpected aspect about the findings was the discussion around reconstructive surgery during the family/social experiences portion. Although the interview guide never specifically addressed the subject of surgery, almost all the participants brought this to my attention during their responses. The main reaction received regarding surgical treatment for facial differences alluded to the idea that it was

both a beneficial and positive step towards helping them function as well as build a

positive self-concept/image. One participant with a unilateral cleft lip and palate stated, "I

had the Rhinoplasty at age 14, which I think helped a lot with my self-confidence."

Another participant also found surgery to be beneficial in terms of dealing with other peer

members:

> During the summer of eighth grade I had major reconstructive work, and that created
> a big difference. Like before I was teased a lot for my differences and speech, but
> when I went back to school after surgery some of the teasing had stopped.

In general, many of the participants had multiple surgeries (most starting in childhood

and maybe continuing onto adolescence or early adulthood) and felt that with each

procedure, their self-image may have improved somewhat as they felt more confident

about their facial features. During the interviews, all women who were born with a

unilateral or bilateral cleft palate had had at least one surgery performed, and it seemed as

if they were perhaps the most satisfied with the outcome of their reconstructive work

(compared to participants whom did not have a cleft palate).

Friends

In terms of experiences with friendships, participants defined that there was a

significant difference between "real" friends and acquaintances. Real friends were

basically defined as people whom you have known for a long time who do not judge you

for your appearances but rather your personality. One woman felt that a real friend was

"someone that you feel a deep level of trust for and understanding with, and you have

known them for a long time and are able to talk about anything." Most participants

agreed that in their personal lives, they would only consider a few people (ranging from

1-4 members) outside of their family to be real friends. For example, one woman with a cleft palate explained her feelings about true friendships and the characteristics that may define a real friend compared to an acquaintance:

"I guess you know....I've always had a few select group of people who are just very good dear friends and I still have them. And I make friends easily, but I regard most friends as acquaintances and not [real] friends. There's only a small group that I would regard in the real friend category…..I feel I have a high level of comfort [with real friends] in what I'm willing to talk about and trust that what I talk about won't be used against me in some way and or repeated….that sort of thing."

Typically, participants felt that the people they encountered on a daily basis (e.g. work, school, social events, etc) were not considered real friends but rather acquaintances. This was because friendships took time and effort to build, as the level of trust and being able to look past their facial differences was critical in fostering any close relationships to flourish.

When asked about when and how these real friendships had developed, an astonishing number of participants stated that they're closest and best friends were actually from elementary school or early childhood. Many said that they first became friends with these individuals during first or second grade, and had since remained extremely close with one another. One woman mentioned that "best friends can go through anything, two of my closest friends are still from childhood." Although distance may have physically separated some of these friends over time, they currently seemed nonetheless just as loyal and supportive to participants as friendships that were developed in adulthood. In addition, many of these early childhood best friends played a critical role in the level of social support and belonging they felt in school. A woman with Apert syndrome recalled "when boys teased me [in school], I felt lucky because I had a group

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of friends to turn to." Similarly, a number of other participants also remembered being teased or meanly treated by peers at times, but they knew that they could always depend on their true friends for comfort and safety. Therefore, this encouragement and compassion that was offered by their friends provided a steady amount of support that was advantageous and appreciated even today.

 Most Comfortable and Challenging Social Experience

All participants were asked during the first portion of the interview whether there was a social situation that they felt most at ease in and why. The responses to this question were mostly split into three subgroups, mainly categorized into close friends, family, and neutrality because they currently felt comfortable in all social circumstances. Most participants felt that with close friends or family, they were best able to just be themselves and felt very comfortable because there was no fear of judgment or focus on their facial difference. Especially within the small group of women with facial differences other than a cleft palate, everyone felt that being with a small number of people (ranging from 1 to 4 members) that were either close friends or family was where they felt most content and relaxed. One woman with Freeman Sheldon syndrome said, "I prefer 1 on 1 conversations with close friends, like we can chat and I'm comfortable with that."

For participants who felt neutral, they explained that they could not think of or pinpoint a particular social situation that would be more comfortable compared to other circumstances. For example, one participant with a cleft palate shared how she felt there was not a social situation that she did not feel comfortable in:

"I don't like doing certain activities, it's not my cup of tea. But I mean I'm definitely not uncomfortable [in terms of her facial difference]. I just don't think there is a social situation where I'm uncomfortable in."

However, it was noticed that only women who were born with a cleft palate responded with the more neutral stance, while participants with other facial differences mainly provided answers including friends and family. The only participant whose response varied from the above three subgroups was the woman with an acquired facial difference. At the time, she felt "most comfortable being alone because I didn't have to worry about what I looked like." It is worth addressing that this participant had to also deal with the change in her physical appearance, while participants with congenital facial differences did not. This added layer of adjustment was difficult, and may have led to feelings of fear, anger, and loss of identity. Luckily, this participant has had a very successful recovery outcome over the years and currently does not find her scar to be especially bothersome.

Participants were then asked to consider and discuss a social situation that might present to them as most challenging and why. An overwhelming majority of women mentioned that being around people whom they did not know was a difficult process. This was mainly due to the fact that strangers may react negatively or make the situation awkward because of their appearance. One woman said, "I did have the initial anxiety and stress about grocery shopping or events, because you never know how people may respond." Although a negative response may not always occur when meeting new people, many women were still anxious about the staring, whispering, and overt comments made in public. Others felt shy or uncomfortable because they were aware of the importance of appearance and how that may affect first impressions. One Black/Puerto Rican woman

with a unilateral cleft lip and palate talked about her concerns regarding making an impression with others:

> "Going to meet new people, those are situations where I'm most uncomfortable. Specifically, going into situations where I have to present myself and make an impression about myself….I'm afraid of what they are going to focus on, like making a first impression."

Therefore, a lot of participants were never quite sure if a stranger would be able to see beyond their facial difference and get to know their personality instead. Included in this category of unfamiliar people were also children, as quite a few women talked about the challenges of hearing and seeing children's inhibited reactions. Also, the teasing and disrespectful remarks made by some strangers were hurtful to their self-confidence and esteem, thus making being in an environment with unfamiliar people one of the most challenging social situations.

<p align="center">Employment</p>

The third question of the interview involved employment, as this issue was further explored by asking participants to briefly characterize their work experiences. Including if there was anything significant during the recruitment process, and their current thoughts and feelings around work in relations to their facial difference.

Recruitment

The general consensus regarding the recruitment process was that having a facial difference produced no significant effects on the hiring procedures during their experience. In fact, the majority of women felt that they themselves probably noticed their imperfections more than their interviewers did. Participants in most cases did not

feel discriminated against due to their facial difference, and perceived the recruitment process to be "fair and reasonably pleasant."

Other Work –Related Experiences

Participants also discussed how they felt about their overall work experience and relations with other professionals. Similar to the recruitment process, the majority of women felt pretty content about the treatment they received from employers and fellow staff members. Within this group, about half the women also believed that their facial difference was advantageous in contributing to a more dedicated work ethic. As one woman with Freeman Sheldon syndrome described, "I worked really hard because I was trying to prove that I was an excellent employee and it felt good to have others recognize my work. That challenge was good." Similarly, many other women have described how they were able to use their past experiences and knowledge gained about living with a facial difference to help others who may be in comparable situations. For example, one woman mentioned, "I used my position as a substitute teacher to talk about people who looked different, it was a teaching tool and has helped me in a lot ways." Other women who have gone into health-care fields or non-profit organizations were also able to rely on their previous experiences of living with a facial difference to help other people.

In addition, due to the frequency of exposure to new environments and social situations, the women in this group felt their professional experiences had somewhat helped them become less anxious around others. Overall, participants expressed that they worked hard to do well in their jobs because it provided a sense of satisfaction and achievement from all their dedication and commitment to their work.

Unlike the positive experiences of the previous group of women, a few participants felt that their position at work was more challenging and had experienced differential treatment based on their physical appearance. These women sometimes felt targeted at work by other employees/employers, or felt that they were seen as less capable in their professional abilities than women without facial differences. For example, one woman talked about her impression of the recruitment process in relation to her facial difference:

> "I had an internship and somebody knew me and referred me so I got this job. I have to work a lot harder to get things done than people without facial differences. I've found that I need to know somebody in order to get an interview, and when I go on my own, I have found it to be unsuccessful."

In addition, the same participant elaborated on a specific situation at work where she felt she might have possibly been denied a promotion due to her appearance:

> "I haven't been given the opportunity to do more in my job because either somebody whom supposedly is more skilled comes along, or some other excuse comes up for me not being promoted."

For others in this group, working in public (e.g. retail, school) could sometimes be difficult because people may stare, make inappropriate comments, or ask questions that would lead to another explanation about why they had a facial difference. Also, some women within this group felt that during the beginning of their jobs, their co-workers seemed "curious but were never straightforward in talking about their facial difference." This produced a rather awkward dynamic at work, but did seem to dissipate or at least decrease over time. However, most participants would have rather preferred their co-workers to be more forthcoming and respectful rather than avoidant in these situations.

As one participant said, "they could of just asked in a respectable manner and I would have told them the truth."

School

After questions in relation to employment, participants were then asked to talk about their school experiences. Initially, some participants were a little uncertain of which school years they should discuss because the question did not specifically focus on a particular time. So participants were told to talk about any time during school that they felt comfortable sharing, especially if the experience was related and significant to their facial difference. The general topics of discussion for school seemed to center around two subgroups, mainly elementary through high school experiences and social relationships during this time.

Elementary through High School

An overwhelming majority of women (with congenital facial differences) discussed that early adolescence, or Middle School, was the toughest time in terms of adjustment and their social-emotional well-being. As noted earlier in the friendships/social experiences section, many participants recalled that early childhood (kindergarten or elementary school) was when they felt very accepted because many of their peers seemed to not yet recognize certain social differences. One woman recalled that "little kids" (kindergarten through 1st grade) were good, because if you looked different it wasn't torture." Elementary school was also when a large number of participants had developed extremely strong and long-lasting friendships with a few other classmates. Quite a few women talked about how their friends from elementary school

were still some of the people they were closest and most comfortable with currently in life.

The interview responses strongly alluded to the fact that the hardest years for most women were during middle school. The main concerns and reasons for this seemed to center around a dramatic increase in teasing, bullying, and harassment from peers. Comments such as "what the hell is wrong with your face?" or name calling such as "cash register" and "freak" were particularly hurtful. Although a few women within this group felt there were times in elementary school where peers made fun of their facial difference, most women did not believe it was to the extent that it had been during the transition into middle school. Many participants also mentioned that more boys than girls teased them, and often it was the boys that made the harsher and more hurtful comments.

In addition to experiencing a lot more prejudice and mockery during middle school, many women also felt they had internalized many of these negative messages and that affected their self-concept and self-esteem. In one instance, a woman with a unilateral cleft lip and palate remembered being compared to the only other student (a young male) growing up who also had a facial difference:

"We were in the same homeroom through out childhood, and they [other students] would always say we would get married because we looked like freaks. So we avoided each other. It was weird because it was like looking in a mirror and I wondered, did I really look that bad?"

As early adolescence was already an awkward and confusing time for most young people, it seemed extra challenging in some cases to also have a facial difference.

Fortunately, High school was a time of positive change and maturity for most of the participants that were interviewed. After middle school, many women commented on

how high school was a much more liberating, and sociable time in terms of their overall experience. A lot of women talked about a decrease in teasing and bullying from peers, and interpreted the change as their fellow classmates maturing and becoming more tolerant of differences. It was during high school that a number of participants within this group felt optimistic and hopeful about belonging into society and feeling accepted by their peers. One woman described that she focused her "energy on science and math as I was very good at it. I also became very active and people became more interested." Another participant commented, "I felt a whole lot better in high school, like maybe I was passing into a society where I may be accepted and known for who I was on the inside."

Many women claimed that during high school, they probably had some of the same concerns as other young women their age without facial differences (e.g. weight, make-up, clothes, etc), and considered it a normal aspect of adolescence. An interesting concept that was mentioned several times by women in this group was how cosmetic surgery had helped them cope and deal with the stressors surrounding appearance in school. Many participants noticed that if the outcome of the surgery were good, they would receive less negative attention towards their facial difference, and at times positive reactions. A woman with a unilateral cleft palate said, "After I had most of my surgeries and my facial difference was less noticeable, I felt my body image started to improve and things became easier." Therefore, surgery seemed to have helped several women feel more "normal" and accepted during their childhood and adolescent years in school.

In contrast to the previous responses, there was one participant with Robinow syndrome that had a considerably disturbing experience in school. This incident stood out

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from other participants as it involved a teacher rather than a peer. Unlike the experiences of most participants, she had categorized both her elementary and middle school to be difficult and unpleasant. During first grade, she was actually bullied and harassed by her teacher who exposed and targeted her as being "disfigured." She remembered that her teacher would make indirect comments about her syndrome (a rare condition that affects the growth of her facial bone structure), and also hit her knuckles when she answered a question wrong. Due to the treatment she received from her teacher, she remembered feeling quite traumatized by the whole experience. Eventually, her parents intervened and a new teacher replaced her old instructor. Her new teacher did not treat her as "different," and the participant really appreciated the fact that she was no longer subjected to feeling singled out from the rest of her classmates:

> "I was told that I was just like anyone else and could do anything I wanted to. This reinforced my self-worth, and although it did not shield me from the teasing, I learned to navigate through things my own way."

This woman felt that by allowing no special treatment in school, she was given the valuable opportunity to explore and resolve her own problems. She knew that there would always be others who may judge her based on her appearance, but she felt more confident of handling these situations by experiencing life as a regular child.

<u>Social Relationships in School</u>

The area of social relationships was the other main issue that arose when participants spoke about school-related experiences. Within this group, women specifically mentioned friends and the importance of peer support, as well as concerns and curiosity regarding boys and dating during adolescence. The majority of women mentioned that even although they were not "popular," their small group of close-net

friends played an important role in sustaining their self-esteem and comfort level at school. Having at least one good friend at school offered a "sense of emotional security and support," especially around teasing or bullying from other schoolmates. One woman had this to say about her childhood friends, "these people protected me from others who tried to hurt."

As most participants grew older and entered into puberty, they inevitably became increasingly interested and curious about attraction and relationships. Similar to their peers, they would often think about their developing "crushes" and talk amongst their friends about boys. However, there were some similarities and differences between participants with cleft palates versus participants with other facial differences.

The most common concern among participants with cleft palates had to do with kissing, and being worried about whether they would kiss the "same way as someone without a cleft palate." Surgery to fix the cleft lip and palate also seemed to help one feel more secure about their mouths and ability to kiss "normally." One participant remembered feeling self-conscious and anxious in the beginning about kissing, but later realized that she did not need to worry so much:

> "I remember when I first started kissing I was nervous about the fact that I had a scar on my lip and I really didn't have much of an upper lip because of my cleft palate…. and then when I first started french kissing boys, it was like 'oh my god!'….But they never complained so I guess it was all good!"

It was certainly not uncommon for women with or without a cleft palate within this group to feel anxious about the way they were viewed by the opposite sex (young males in this case). Many had felt ignored or teased by boys in school, so they were apprehensive about whether people found them attractive and interesting later on in life. Almost all

women interviewed felt dating and relationships were challenging in school, as most participants either did not date or dated only a few times. Some even had disastrous experiences or pushed away those that may have been interested, in fear of rejection or refusing to believe that anyone would want to date them. One woman humorously remembered how she "pushed a lot of guys who were interested away or avoided them, cause she couldn't believe they really found her attractive." Encouragingly, many participants felt that as they matured in age, they were also exposed to more people in numerous environments. This experience has made some women recognize, achieve, and maintain a very successful and enriching relationship that is highly valued and respected.

The final and most prevalent similarity between all groups regarding school was a definite desire to have more psycho-education and contact with people with facial differences. Although this ties into the next section of the interview about positive coping and methods of learning, participants seemed to have wanted teachers and peers to be more sensitive and knowledgeable about respectful treatment of anybody with visible differences. Many women said that their "teachers didn't know a lot about facial differences nor were they required to attend educational/training programs around the issue." Therefore, teachers were usually not equipped to handle the social conflicts or challenges that occurred in the classroom.

Furthermore, an overwhelming number of women said that growing up, they rarely if ever met another person with a facial difference. One woman with a unilateral cleft palate and lip recalled, "I was the only one like me in the entire school." This led to a strong feeling of being vastly different than other children, and at times left memories of isolation and sadness about not fitting in or being accepted by society. In particular,

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one woman with Fibrous Dysplasia had so little information and exposure to other people

with similar conditions that she first learned that there were others like her through a

movie:

> "At 9 years old, it was really rough thinking I was the only one in the world like me. I didn't know there were other people like me until I was grown. [When asked how she found out that there were other people like her]….Well, it sounds kind of awkward but it was the movie 'Mask.' ……I watched it and was amazed that there was someone else in the world with facial differences."

It was a difficult experience for many women with facial differences growing up because

there were so few psycho-educational programs. Essentially, a lot of participants felt that

it would have also been very valuable to meet other people with facial differences (in a

safe and contained environment), as it would have provided a sense of twinship and

connection with people similar to themselves.

<div align="center">Positive Learning and Methods of Coping</div>

The final question asked participants if they would mind talking about any helpful

or meaningful ways of dealing with a few of the discomforting situations that they had

described in relation to their facial difference. It was explained that one of the main

purposes of my study was to further understand and appreciate the positive adaptations

and coping mechanisms that women have found helpful during times of adversity. It is

perhaps their personal accounts of what has been helpful that may provide a useful source

of strength and hope for other people who may be dealing with similar situations based

on their own facial difference. The powerful responses that were received could primarily

be summarized into four categories: positive acceptance, faith in a higher existence,

community outreach/activism, and being involved in groups with other people with facial

differences.

<u>Positive Acceptance</u>

The concept of positive acceptance was the most common idea that had been recognized as helpful for women in this study. Positive acceptance meant being "content and at peace with one's physical attributes (including both good and bad features), and realizing their inner beauty and self-worth." In general, participants felt that being accepting of themselves and their facial difference was one of the chief paths towards living a happy and fulfilling life. Fully believing and knowing that one is worthy of attention, love, and affection from other people and themselves was in some ways therapeutic, as it helped many women prioritize what they felt was really important in life. What was humbling about their responses was that almost all the participants acknowledged that their level of self-acceptance fell more on a spectrum rather than one particular position. This meant that their self-esteem, confidence, and self-image could fluctuate depending on certain social situations (e.g. bad days). For example, one woman shared, "If I'm having a bad day, then I'll probably cry about it and not feel so great about my body image." However, the important and similar component to most participant's answers was that if they identified as being accepting of their facial difference, then on most days, they loved their bodies and appreciated themselves for the way they were.

Many participants remembered that it was <u>a</u> much more difficult process to fully accept their facial difference during childhood through late adolescence. It was possible that part of their young mindset at the time may have contributed and impacted their self-esteem, self-image, and the development of relationships with others. Therefore, the journey towards self-acceptance and reinforcing the positive attributes rather than the

negative has not always been an easy process for many women. For example, one woman

described acceptance as being critical, because "first we must accept ourselves before we

can help others accept us."

The uplifting and admirable piece of their stories was that currently, almost all the

women that were interviewed felt either fully accepting or at a very high level of

acceptance in terms of their facial difference. This meant that overall, they were satisfied

and contempt with their physical appearance, and have made a conscious choice to filter

out a lot of the negativity that they may encounter. This has helped many women put

things into perspective, as they have learned that what is important in life is not how one

looks, but rather how one acts and treats other people in society.

<u>Faith</u>

Similar to positive acceptance, many participants felt that faith in a higher

existence or being (e.g. God) was a helpful resource in dealing with the difficult social

and personal challenges in life. A significant number of participants felt that having faith

was a valuable tool in understanding and dealing with their facial difference. For

example, one woman with a cleft palate explained how she believed that faith had been a

positive source of learning and method of coping:

> "Definitely it's my faith in God, and I'm thankful to be born this way because if I
> hadn't, I would probably not be as sensitive or caring towards other people. I
> understand that we were all created as beautiful beings and for a reason, it's a
> beautiful thing."

Having come to terms with her facial difference, this woman appreciated her faith

in God because it helped her find meaning associated with her condition. It may have also

provided a sense of resolution, as she was able to fully accept herself without resentment

or anger for why she was born with a facial difference. On a side note, a few other women within this group who also believed faith was an important resource mentioned that surgical procedures and recovery was less frightening (or anxiety provoking) knowing that they could always turn towards a higher existence or being for support.

Activism

For the majority of participants, giving back to the community and helping others had been a successful way of achieving satisfaction and a sense of fulfillment in life. A few examples of community outreach that participants had done included volunteer work at camps, reaching out to families of children with facial differences, and presenting at or attending conventions dedicated to providing facial differences awareness. The women seemed to feel that being active in the community was one of the most meaningful and enriching aspects of their lives. A lot of participants felt they did not receive enough support and educational resources about facial differences growing up, and now are dedicated to advocating and contributing to this area of need. For example, one woman worked in the pediatric field and enjoyed helping children and their families, "I like working with children with facial differences and their families. Patients come to me for advice and to hear my stories, it feels good to be able to offer guidance and a voice." The ability to play a proactive role in helping young people seemed to be extremely gratifying, as most participants agreed that there was currently not enough awareness or work being done to address the many challenges that people with facial differences may encounter. It was also mentioned that in addition to support and outreach for children, there should be more services available for adults, as opportunities like these would benefit people of all ages.

<u>Groups</u>

Participants frequently suggested that joining a community or group with other people who have similar shared experiences was advantageous for women with facial differences. It was recommended because verbally sharing one's stories of experience (both successes and challenges) was helpful in that it could create a potential bond and relationship with others. Many admitted that to really open up and talk about some of the tougher issues was "nerve-racking" at first, but they were glad they had the courage to do so. It was important for all of the women to surround themselves with people who were sensitive, caring, and reinforced their strengths and positive attributes. As one woman cited, "I think it's important to surround yourself with positive people that make you happy and expect good thing out of you."

Having an encouraging point of view and being with positive people may help build a sense of belonging rather than isolation, as group members provided camaraderie and connection in the world. As stated earlier, having a steady social support system through out life seemed to foster a stronger link with other people and a more positive outlook on life and for themselves. Many participants felt that growing up, they did not have the option of attending social support groups or even meeting other children/adults with facial differences. Upon reflection, participants would have greatly appreciated this opportunity to come together and learn about other people with similar struggles and life experiences.

In addition to social support groups, a significant portion of participants would have also wanted some type of social skills training. The training may include but would not be limited to practicing and learning some strategies around dealing with

uncomfortable social situations that one may encounter. Some women also wanted to be able to first rehearse and apply some of these various responses learned in social skills training with their fellow group members. One woman suggested that it would be great to "role play and practice conversations with others, like looking people in the eye and communicating effectively." The group may provide a safe and non-judgmental environment to really practice and feel more confident before testing out these newly learned skills in everyday life. Then afterwards, there could be discussion about the exercises done during social skills group so that members may reflect and express how that experience felt. Therefore, participants proposed that having social support and skills training may be a very useful way of learning how to become more assertive and successful in meeting one's needs despite having a facial difference.

<u>Intimacy</u>

At this time during the interview, all participants were informed that this last question regarding intimacy was completely optional, and would not affect their participation if they did not want to answer. Using the interview guide, the question was first read to all participants, and then everyone was given the option of continuing to talk about their experiences or having the interview conclude without further questions. It was also mentioned that the literature review regarding facial differences included very few findings around the issue of intimacy. Therefore, this question was included at the end of the interview so that if any participants felt comfortable with the subject matter, they would be helping to contribute and broaden the current understanding of intimacy within this group. A surprising 12 participants agreed to discuss the topic of intimacy, and the responses seemed split into two subgroups. The first being women who were currently

very happy and fulfilled in terms of their intimate lives and did not feel their facial

difference had a significant effect on intimacy. While the second subgroup of women felt

that their facial difference played a bigger role, including affecting areas such as body

image, perceived level of attractiveness, and comfort around potential partners.

<u>Facial Difference Not Affecting Intimacy</u>

Women who responded with a high level of satisfaction and contentment

regarding their intimate lives composed almost half of the responses related to intimacy.

However, it is important to note that all the women who belonged in this subgroup where

either married or involved in a serious relationship (e.g. engaged, dating for many years).

The reason this may be significant was that many of the women mentioned how their

spouse or partner made them feel completely comfortable and attractive, a feeling which

they did not necessarily receive from relationships in the past. Therefore, it may be

possible to speculate that women who were in serious monogamous relationships for this

study felt that their attractiveness and views about intimacy have been positively affected

by their loving partners. For example, one woman with a unilateral cleft lip and palate

described that her husband made their romantic life "terrific" and she felt "completely

comfortable and beautiful with him."

It is important to identify that within this group, almost half the women felt that

their intimate lives and self-image had changed in a positive way after meeting their

spouses. One woman explained how her trust became so strong with her husband over the

years they've been together:

> "I guess my advice would be to not pre-judge your partners, and try to be open and
> honest and don't push anyone away…..Let your heart be open because I have been
> with my husband for twenty-two years, and I met him as a teenager. Before my

husband I only went on double dates…..and at first I was worried about my facial difference and that he was too good to be true. I thought he might feel sorry for me, but slowly I learned to trust him."

Thus, the majority of women in this subgroup related their intimate lives in a positive light, and provided a hopeful outlook on intimate relationships based on their strengths, level of trust, and the amazing role that one person may fulfill in someone's life.

Facial Difference Affecting Intimacy

For women whose feelings regarding intimacy had been impacted by their facial difference, romantic relationships seemed to be challenging in that many women have struggled to find long-term connection with romantic partners. All of the women in this subgroup were not married, but had gone through at least one previous dating experience while some had just begun a new relationship. Also, a few women in this group were involved in long-distance relationships from people they've met online, or through Internet support groups related to facial differences.

The one common aspect that all women shared in this group was that they felt anxious about their facial difference and how others may respond or reciprocate to their feelings of attraction. Also, many participants mentioned that because their strengths were not emphasized very often by peers or reflected in society, they struggled to find positive traits that others may value. One woman with a bilateral cleft palate mentioned how she really wanted to highlight certain positive attributes and went through extreme measures to do so:

"I think for me part of it was related to my cleft palate…..I think I definitely had an image of myself that I wasn't as pretty as the other girls or as attractive….I did know that I was always thin and got a lot of positive feedback about that. So as I got into my teenage years, I remembered being more conscious about my body because it was the one thing that people were always like, 'Oh my gosh, you are so thin. You

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can wear anything,' so I wanted to keep that."

As noted earlier in the positive learning and methods of coping question, it was common for a women's body image to fluctuate depending on the circumstances. However, during her battle with an eating disorder, this woman felt that her only positive quality was to remain thin because she believed the rest of her appearance was flawed. Fortunately, through different modalities of treatment such as individual and group therapy, she was able to adopt a healthier body image and a more positive lifestyle.

Through out the last part of this interview, having anxiety and feeling self-conscious were often mentioned, especially if someone had been teased or bullied in the past during school. This might have led to an increased level of worry and concern around the issue of intimacy, thereby affecting one's confidence regarding the opportunities available for meeting someone who may overlook their facial difference and provide enough sensitivity and care for trust to fully develop.

<div align="center">Summary of Findings</div>

The information discussed in this chapter both reflects and characterizes the personal experiences of 14 women with facial differences through direct phone contact using a structured interview guide. The responses mainly demonstrated that even though all the women who participated have encountered life challenges (of various degrees) based on their appearance, most have learned from these experiences and have developed many helpful methods of coping. Specifically, participants commented in detail regarding the knowledge that they have gained through areas such as friends and family, employment, school, and intimacy (optional question).

In addition, the majority of women had an optimistic and positive outlook on life and valued trustworthy friendships and relationships. They believed faith and acceptance were important because they provided a sense of support and rationale for understanding why people were born the way they were, and this helped contribute to many women's own sense of contentment with their appearance. Almost all participants no longer felt the strong desire or need for approval from people in society that they were unfamiliar with or had no relationship to. This was mainly because they were receiving genuine and sufficient support, care, love, and acceptance from the people in their lives who did matter (e.g. close friends, family, and partners). Finally, the majority of participants were open and willing to discuss the aspect of intimacy, and mentioned a variety of thoughts related to their experiences regarding romantic issues and relationships. As the interview came to a close, all 14 women had expressed enthusiasm for having participated in this study to help further deepen and explore the experiences of women with facial differences.

CHAPTER V

DISCUSSION

The purpose of this study was to further understand and learn about the advantageous ways in which women with facial differences have dealt with some of the more challenging aspects of their everyday lives. One of the goals for interviewing participants in depth was to listen, recognize, and appreciate each woman's personal experiences so that it may broaden the general knowledge around facial differences and possibly bring hope for other people in similar circumstances. Upon reflection in this chapter, I will address and evaluate the importance of this research, along with my own learning regarding the accessibility and future implications around this study.

<u>The Importance of Research on Women with Facial Differences</u>

Early on, I learned from both participants and through previous research just how concealed and underrepresented people with facial differences were to the general public. Although it may not be uncommon for anybody to encounter or know someone with a facial difference, the stigma and negative stereotypes that may be associated with people from this population were rarely addressed in either the individual or institutional level. If one is fortunate, then exposure, discussion, and possible social training may be provided for families and friends of individuals with facial differences. However, with little public acknowledgement and understanding of the experiences of those with facial differences, I was passionately interested in finding out some of the ways a person with facial

differences may positively cope, learn, and adapt to their environment. Furthermore, I specifically chose to study women, as they have historically been an underrepresented population, adding gender as another level of discrimination in addition to having a facial difference for participants. The age of participants was narrowed down to adults between 18 and 50 years old, as the interview guide would not fully apply to most participants who were younger or older (due to being in a different life stage) than the required ages. Finally, due to the estimated availability and accessibility of participants, both women with congenital and acquired facial differences were asked to participate in this study.

One unexpected characteristic about participants in this study was the overwhelming number of women with congenital facial differences compared to acquired facial differences. The majority of women were either born with a unilateral or bilateral cleft lip and palate. This sample of women with facial differences was a contrast from the earlier research in the literature review chapter, as the literature review did not focus specifically on any participants with a cleft lip and palate. More studies have been done with people with acquired facial differences (e.g. burns, cancer) and congenital facial conditions other than a cleft lip and palate. Therefore, the findings from this study may not fully encompass, reflect, or apply to the conclusions found in the literature review. The surprising ratio of so many more women with congenital facial differences than acquired was not a prospect that was foreseen, nor was the number of participants with a cleft lip and palate.

Upon evaluation, I believe the focus of my study was both enriching and beneficial to the field of facial differences study in clinical social work. Although the information gathered from my research was limited and only represented a small sample

of the overall experiences of women with facial differences, I do consider it productive and useful in broadening our awareness about the positive adaptive coping mechanisms used by some women. The participants often elaborated in detail about their experiences, and shared ideas about what they have found helpful so that others in need may also take something away from their sincere stories. After the interview, many participants expressed how talking and relating their experiences for the purpose of this study was advantageous to their own sense of self, as it provided an outlet for reflection and possibly growth. Another gain for participants was that they were eager and excited about sharing their knowledge and expertise in order to help other people with facial differences. This opportunity was highly valued because of the lack of awareness and education regarding facial differences for the public, so being able to contribute and inform others in a helpful manner was perhaps the most fulfilling aspect of being in this study.

<p style="text-align:center;">Women with Facial Differences As An Open Topic of Study</p>

As mentioned earlier, the availability and accessibility of recruiting women with facial differences as participants in a qualitative research study was a concern. However, I have found women with facial differences to be a population that is open to current research, and can indeed be studied in depth. I have also recognized that one helpful way to find possible participants and more information about recruitment is to contact someone who is already involved in working with people in this population. For example, contacting a director of a non-profit organization dedicated to working with people with facial differences may be a useful way to begin the process, as it may be critical to first find out where and how participants may be recruited. In this case, there are several

online Internet support organizations for families and people with facial differences. Therefore, I was able to make the appropriate contacts and receive guidance and information about participant recruitment. I have found that when recruiting participants for qualitative studies of sensitive issues, it may be beneficial for your contact person to first introduce you (e.g. over telephone or through e-mail) and your research study purpose to any possible participants. This helps create a less alien and more familiar introduction as both you and any interested participants would at least know one mutual person in the process. Also, researchers should not expect people to immediately trust you or convey great interest in your study, so having your contact person who already knows your population may help open doors for a more successful recruitment.

Once participants have expressed interest, it has been my experience that using e-mail (or brief phone conversation) is the best way to keep in touch and set up an interview time. Keeping conversations friendly, casual, and at time humorous may help create a more relaxing atmosphere during the actual interview. Participants should also be encouraged to ask questions or take breaks when needed. I have found that using direct over the telephone interviews (as participants were located all over the United States) along with a few open-ended questions followed by prompts or probes (when necessary) seemed helpful. Participants were given the freedom to provide as much information as they felt comfortable doing so, but were not limited to answering questions that were specific or broad. The categories selected for the interview guide were based upon the literature review in hopes of adding to or further developing understanding of a few significant areas of life that may impact these women on a daily basis.

Central to this study was the shifting of focus from negative experiences to recognizing and elaborating the positive adaptations and methods of learning that had occurred for the women. Although participants were inevitably going to recall negative experiences and memories, this information was more often used to build on what participants have learned and used from these experiences to presently tolerate any challenging aspects of their lives (related to their facial difference). I believe working with participants from a strengths perspective rather than a deficient point of view was helpful. For example, my contact person suggested using the term 'facial difference' rather than 'facial disfigurement,' as the first term proved much less pejorative and concentrated more on a person's strengths and individuality. It was also remarkable to hear how satisfied and confident many of these women were about themselves currently, and how they attained that high level of self-acceptance and was something I wanted to highlight and identify in this project.

Overall, the study mostly likely provided participants with the opportunity to educate and possibly reach out to other people (especially women) in similar situations. In my opinion, the need for this kind of outreach, awareness, and community activism is apparent and needed in our society. Although learning and exploring the discriminatory experiences of disadvantaged populations is vital in deepening our understanding of people with facial differences, being proactive and reaching out to people in a positive light may be just as rewarding and critical for advancement in facial differences awareness.

Future Implications for Study

In general, the research and findings of this study have proved to be constructive and useful. The aim of this project was not to prove, but to hopefully create more awareness and help build on the already existing knowledge about women with facial differences. Upon reflection, I believe that this study has several areas that may be modified, adapted, or added for future research on this population. This includes possibly recruiting participants of different gender, age, race/ethnicity, and nature of facial difference. It also means broadening future research to incorporate areas such as surgery and intimacy, while limiting other categories such as employment.

Participants

Future research in this area might possibly include male participants, as this study was limited to only women. It would be valuable to find out in more depth and detail about the experiences of men in relations to social functioning and methods of coping that may have developed. This current study also lacks the ability to compare and contrast between gender groups, so upcoming research may want to look into similarities and differences between and within male and female participants with facial differences.

The current study also does not include people under the age of 18 or over the age of 50. Even within this specific range of ages, there were no participants under the age of 25 so young adults were not accounted for in this study. Therefore, research modified to focus specifically on children, adolescents, or the elderly may be needed to gain a more comprehensive understanding of this population. Once again, gender may be a factor to consider, as there may be significant differences or similarities between or within genders

and certain age groups. Nonetheless, age would probably be an important characteristic to consider for future studies with people with facial differences.

In future studies, it may be critical to further examine more participants with acquired facial differences as their experiences may differ from participants with congenital facial differences. For this study, an unexpected and surprisingly large sample of participants had congenital facial differences rather than acquired. Consequently, the findings gathered from the interviews mainly reflected women who were born with congenital facial differences. However, studies with a focus on participants with acquired facial differences are needed because unlike congenital differences, participants have the added layer of experiencing some kind of change in their physical appearance. If trauma were also present, then that additional factor would be another possible major difference to look into between acquired versus congenital facial differences.

In particular, this study included a self-selected sample of women who voluntarily participated, making it reasonable to speculate that this group of women have adjusted and adapted quite well to their facial difference. The overwhelming prevalence of women with a cleft lip and palate compared to other facial differences may also suggest it is condition that people are best able to deal with. As one of the more common congenital facial conditions, it may not seem as permanent at the presenting level because of the surgical addressability and successful outcome in many cases. Still, future research involving a more random sample of participants is needed to better understand the experiences of women who may not feel as well adjusted or accepting of their facial difference.

For this project, the role of a participant's race and ethnicity was not studied as the overwhelming majority of women identified as White/Caucasian. Previous screening of participants did not include race/ethnicity, but all participants were asked during section I of the interview (Identifying Information) to state their racial identity for statistical purposes. In future studies, it would beneficial to study how one's race or cultural may impact their experiences of adaptation in relation to their facial difference. In addition, people of color who also have a facial difference would experience multiple levels of oppression, adding race as a separate dimension of adversity compared to Whites. Hence, studies in the future may want to explore racial significance for people with facial differences.

Finally, one major weakness of this study is the limited sample size of only 14 participants. Due to restricted time and financial resources, no more than 15 participants could be interviewed in depth for this qualitative study. Although this leaves a vast number of participants and their experiences unaccounted for, future studies could always benefit from increased sample size.

Surgery

During interviews, I was surprised by how frequent and in depth participants discussed reconstructive surgery and it's benefits towards healing and a happier sense of self. Even though earlier research had documented the use of surgery for functional and cosmetic reasons, I did not anticipate the salience of responses that directly related surgery with a person's level of acceptance, better school experience, and ways of coping. Although it was evident in the findings that participants did not believe surgery alone would resolve a great deal, it was shown that surgery did help participants achieve

a more positive sense of self and further acceptance from society. It may be possible to speculate that because participants noticed a friendlier reaction from other people after surgery, that kind of response may have helped contribute to a higher level of self-esteem and self-image. In return, this may have translated into a feeling of being more accepted into society and fitting in with other people who were not familiar with being around people with facial differences.

In future research, it may be of worth exploring in depth how reconstructive surgery may affect a person's level of self-acceptance and self-image. Although there have been numerous quantitative studies done on plastic surgery, it would be helpful to deepen that research by interviewing participants with some open-ended questions. Additionally, it might be important to also look into and compare the meaning and experiences of surgery for participants with congenial versus acquired facial differences.

Intimacy

The optional question of intimacy was included due to a general lack of knowledge and research about this issue in people with facial differences. I was particularly interested in hearing from women about their thoughts on relationships with any partners, and what they have learned about themselves in terms of intimacy. I was amazed because the vast majority of women were willing to contribute and share at least some aspect of their intimate lives, In fact, many women expressed positive feelings regarding intimacy and were comfortable exploring the issue in order to help strengthen this area of research that had previously not really been examined. As a result, I am more prone to believe now that the topic of intimacy may not be such an untouchable one in research. Further studies on intimacy may be useful, as the core idea behind intimacy for

many women seemed to be relationships and the level of connectedness they felt with others in the world.

<u>Employment</u>

One area of discussion that most participants did not find to be particularly important was employment. This contradicts previous research done by Stevenage & McKay (1999) regarding discrimination and it's undeniable presence at work. Stevenage & McKay (1999) mentioned biases in areas such as recruitment, hiring, and the general response or treatment from staff, employees, and employers. However, my research found that even participants with more rare facial differences did not necessarily feel they were treated differently at work. In general, most women could not think of anything significant that was related to their employment in relation to their facial difference, and did not believe they experienced any prejudice. So based on the feedback I received from participants, I would probably remove the question about employment if this study were repeated. Instead, a more direct question may be asked about any helpful strategies or techniques participants may want to share with other people who may feel they are at a disadvantage when it comes to employment matters. This section may be added to the positive learning/methods of coping question so that participants may have the opportunity to provide constructive advice for those who have experienced discrimination in the work force.

<div align="center"><u>Summary of Discussion</u></div>

As a researcher, it has truly been a privilege to interview and work with the many women who have contributed to the research findings for this study. The objective of this project was to expand and enhance the general awareness and understanding of people

with facial differences, and perhaps provide support and hope for anyone who may be struggling to adjust to their own visible difference. In particular, the work focused on women, adaptation, and the advantageous coping methods or strategies that one had learned and wanted to share in their own words. Each participant's willingness to help and openness in response was truly encouraging. More qualitative and quantitative studies are needed in order to further deepen our understanding and awareness of this population.

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Appendix A

December 22, 2006

Fusang Carly Yin
10 Aldrich Street
Northampton, MA 01060

Dear Carly,

Your careful and complete revision has been reviewed and we are now happy to give final approval to your study. Thank you for sending copies of all the sections you deleted, as it made it much easier to follow your amendments. Again, let me say that the material you included was good material and some of it will probably be in your thesis, it was just not necessary to include it all in your HSR Application and particularly in the Consent. You have done a good job of cutting and clarifying your plans.

I did notice one typo in paragraph three, line six of your Consent. I believe you mean *in confidence.*

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain signed consent documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with this most interesting project. The emphasis on a strengths perspective will make it particularly useful for the participants and for others who might learn from them.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Roger Miller, Research Advisor

Appendix B

Informed Consent Form

Dear Participant,

My name is Carly Yin and I am a second year graduate student at Smith College School for Social Work. I am interested in researching and learning about the positive and advantageous ways in which women between the ages of 18-50 with facial differences deal with the social difficulties they may encounter. In order to qualify for participation, you must either currently or sometime in the past have been working (full, part-time, etc.) or in school (full, part-time, taking classes, etc). Also, your facial difference may either be present at birth, or acquired due to some childhood or adult event.

One of the main goals is to listen to and explore from your perspective how you have best negotiated and handled the many social experiences that may have been related to your facial difference. I am really hoping to benefit from hearing about your successes, and the positive strategies you have found to be helpful or valuable in managing your personal and social life. The information collected from this study will be used for my master's thesis in social work and for possible presentation and publication.

As a participant, I will be asking you five main questions through a confidential interview session over the phone that is set up at your convenience. Once I have received this signed informed consent, I will contact you to make that appointment time for our phone interview session. The interview will take approximately no more than one hour depending on the length of responses and details given. The personal information I will need to know (during the beginning of each interview) but will hold in complete confidence through out the entire study will be your name, age, race/ethnicity, nature of facial difference, how long you have lived with a facial difference, and occupation. I will be using a digital voice recorder during our interview, and will also be taking notes during the course of this study. The purpose of the recorder and note taking

is to ensure that I have the most accurate and precise account of the information you are giving. I will also be doing any transcription on a needs basis (e.g. for clarification or analysis), and the transcripts will be disguised and kept confidential.

The risks involved are mainly emotional, and may include discomfort, embarrassment, distress, and feelings of pain and anxiety due to talking about unpleasant experiences. I understand that describing these highly sensitive and personal issues may be difficult and stressful. Therefore, you have the option of not disclosing any information you do not feel comfortable with, and may choose to withdraw from the interview at anytime if you wish to do so. Attached is a list of general referral sources that you may find helpful. I will also be glad to help you identify and look for some possible local resources if desired.

I believe that your participation in this study will be beneficial in several possible ways. I think there is a general lack of awareness about the stigma that individuals with facial differences encounter, and currently there is not enough research regarding women's personal experiences and how they impact oneself. Your contribution to this study will help add a unique and useful dimension to the topic of facial difference in women. It may also be possible that other women who may be experiencing similar feelings and emotions about their own facial differences may feel comforted and supported by your stories and experiences after reading them. During the course of this interview, your personal accounts of strengths and struggles may also offer you the opportunity to reflect about your experiences while educating others. Lastly, you will be entered to win a free 20-dollar gift certificate (a 1 in 15 chance of winning) to Borders Book Store for participating in my study.

Confidentiality will be taken very seriously due to the personal nature of this study. Once the interview session is over, your information will be under a unique code name assigned specially for you, and all information (recordings, notes) will be kept in a locked cabinet to help ensure confidentiality. My research advisor from Smith will be the only other individual who may

have access to the disguised information (no real names used, only codes). During publication

and presentations, the information will be presented as a whole group and any identifying

information will be carefully disguised or removed during any presentations of brief quotes or

vignettes. As required by Federal regulations, all data collected will be kept in a locked cabinet

for three years. After this time, all notes and transcripts will be shredded and the recordings will

be erased.

Your participation in this study is greatly appreciated but completely voluntary. You may

choose to withdraw at any time during or after the study has begun, and may choose to not

answer certain questions in the interview. You will not be penalized for withdrawing, and all

materials pertaining to you will be destroyed. However, you will still be provided with the list of

referral sources and be eligible to enter the raffle drawing. The final date you may withdraw is on

March 1st, 2007. Please feel free to contact me anytime with questions or concerns at

fyin@email.smith.edu. Thank you for your time and effort.

Print Name_____

Signature_____Date_____

Researcher Signature_____ Date_____

**YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE
ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORUTNITY TO ASK
QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS
AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.**

Please keep ONE copy for you own records

Appendix C

Interview Guide

I.   Identifying Information

   A. Age:

   B. Race/ethnicity:

   C. Nature of facial difference:

   D. Years living with facial difference (if applicable):

   E. Occupation:

II.   Friendships/Social Experiences

   A. Ask-"I am interested in your relationships and social life, such as friends,
       family-do you mind briefly telling me a bit about your experiences around
       that?" Prompts if needed may include: "I was wondering if you could talk
       a bit about your family, and which people are significant in your life and
       why?"

   B. Ask-"What would be a social situation that you would feel most
       comfortable in and why?"

   C. Where in your life do you feel most challenging socially and how have
       you dealt with that?"

III. Employment/School (as indicated by participant)

   A. Ask- "Could you briefly characterize what life was like at school or
       work?"

B. Prompts may include: "I was wondering how you felt about the (hiring or recruitment process) or (relationships with other school members), and could you talk a little bit about that experience?"

IV. Positive Learning, and Methods of Coping

A. Describe learning process and what participant finds helpful-"In this last question, I am interested in finding out if you have found any helpful or meaningful ways of dealing with any of these discomforting situations that you have share so far? How so?"

B. Prompts may include: "It may be really helpful for other people to hear about your stories because it gives them hope, strength, and possibly new ideas to help cope with their differences. Have you found any positive gains and strengths that you didn't recognize about yourself before that you might want to share?"

V. Intimacy (Optional)

A. Describe intimacy-"I am also interested in the area around intimacy, would you be willing to talk about that?" If so, "How would you describe your feelings about intimacy related issues?

B. Prompts may include: "Would you mind sharing your thoughts and feelings around a previous or current relationship?"

*The area in each section that says "prompts may include" are all ideas if there is allotted time or the participant is having difficulty answering the more open-ended questions.

Appendix D

Recruitment Form

Dear _____,

My name is Carly Yin and I am a second year graduate student at Smith College School for Social Work. I am interested in learning about the positive and advantageous ways in which women with facial differences deal with the social situations they may encounter. My aim is to listen and explore from your perspective how you have best negotiated and handled the many social experiences that may have been related to your facial difference.

The participants who may qualify for my thesis study include any women between the ages of 18-50 who have either been born with a facial difference or have lived with a facial difference because of some childhood or adult event. Also, you must either currently or in the past have been working (full, part-time, etc.) or in school (full, part-time, taking classes).

I am really hoping to benefit from hearing about your successes, and what you have found to be helpful or valuable in managing your personal and social life. I also hope to hear and learn about how you have best negotiated/dealt with the social experiences related to your facial difference.

The participation time will take no more than an hour (flexible), and will be a confidential phone interview set up at your convenience. All participants who volunteer to be in the study will be automatically entered to win a 20-dollar gift certificate to Borders Book Store. If possibly interested, please give Miss Debbie Oliver permission for me to call you soon to further explore your participation.

Sincerely,

Carly Yin (BA, MSW Intern)

617-816-0262
fyin@email.smith.edu

Carly Fusang Yin
Adaptation, Positive
Learning, and Methods of
Coping In Women With
Congenital and Acquired
Facial Differences

ABSTRACT

This study explored women with facial differences and the various adaptive

pathways and positive coping mechanisms that have developed in order to handle social

challenges. Currently, there is a lack of awareness and understanding about this

underrepresented population, making it necessary to examine women's personal

reflections and perspectives as well as their strengths.

Fourteen women between the ages of 18-50 with congenital or acquired facial

differences (13 congenital; 1 acquired) participated in this exploratory study. Participants

were recruited based on availability and snowball sampling, along with help from the

director of a non-profit facial differences organization. Participants also had to be either

currently or sometime in the past been working or in school. All women were

interviewed over direct telephone contact with a structured interview guide that explored

five main topics: friendships/social experiences, school, employment, positive learning

and methods of coping, and intimacy (optional).

The findings were generally positive and optimistic in nature, indicating a high

level of adaptation and frequent utilization of positive coping skills. Adequate social

support from family and close friends along with self-acceptance and faith were helpful

ways to cope with daily stressors, while community activism and support organizations

or social skills groups were all considered beneficial. Finally, reconstructive surgery was unexpectedly mentioned quite often and considered advantageous by many participants.

Limitations include small sample size and the uneven number of participants with congenital versus acquired facial differences. Future research may consider broadening studies to incorporate factors such as gender, race/ethnicity, surgery, and intimacy.

ADAPTATION, POSITIVE LEARNING, AND METHODS OF COPING

IN WOMEN WITH CONGENITAL AND ACQUIRED

FACIAL DIFFERENCES

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

Carly Fusang Yin

Smith College School for Social Work
Northampton, Massachusetts 01063

2007

ACKNOWLEDGEMENTS

TABLE OF CONTENTS

CHAPTER I

INTRODUCTION

The objective of this study was to explore and identify some of the positive and

meaningful ways in which women with facial differences have dealt with the social

difficulties they may have encountered in society. Women who are disfigured facially

experience many disadvantaged social opportunities, as well as emotional and

psychological distress (Benrud-Larson et al., 2003; Griffin & Langlois, 2006).

Furthermore, public awareness and education about facial differences has not particularly

been publicized or enforced in both the individual and institutional setting (Frances,

2000; Kent, 2000). This contributes to a lack of understanding or consciousness about

this vulnerable population, and becomes problematic because it creates false assumptions

and discriminatory acts. These negative beliefs may also then be internalized and

reproduced in society, causing much personal distress as well as deprived social

opportunities for those living with facial differences (Clarke, 1999; Stevenage & McKay,

1999). As a result, the empirical data collected during this research also aimed to help

expand and add to the knowledge about women's adaptation, response, and resiliency to

facial difference.

For the purpose of this research, the term 'facial difference' has been chosen to

describe any participant who feels they have a disfigurement of the face (whether

congenital or acquired later on in life during some childhood or adult event). Early

exploration on the accessibility of eligible subjects led me to speak to organization

leaders dedicated to helping this population, and it was through them that I learned the

term 'facial disfigurement' was rather pejorative. Therefore, the term facial difference

has instead been used to define my population.

Although previous research have been done in this area of study, they are

usually quantitative in nature do not as often examine the more subjective and personal

accounts of women living with facial differences. The current literature steadily reports

that the majority of individuals with facial differences have difficulty with social

interactions because they do not feel accepted or comfortable in public situations (Clarke,

1999; Kleve et al., 2002; Papdopoulos et al., 2000). Women in particular may have

additional challenges to encounter since so much emphasis is commonly placed in our

society on physical appearances and attractiveness (Benrud-Larson et al., 2003; Griffin &

Langlois, 2006). The literature also highlighted various findings related to school

experiences, employment opportunities, and social relationships (Stevenage & McKay,

1999; Frances, 2000; Kent, 2000), while the topic of intimacy was rarely if ever explored

in detail. In addition, the areas of positive learning, advantageous coping methods, and

resiliency in relation to having a facial difference were also not frequently covered in

research. Thus, this qualitative study along with a concentration on adaptation and

participant's strengths was conducted to further assist in learning more about the

experiences of women and facial differences.

Overall, this study examined adaptation and the positive strategies for coping

in 14 women with facial differences between the ages of 18-50 through direct telephone

interviews. Related questions in four areas including friendships/social relationships, school, employment, and intimacy (optional) were also explored in depth with open-ended questions from a structured interview guide. The information collected was used to identify both the negative and positive psychosocial consequences of living with a facial difference, and participants shared some personal insight as to what they have found helpful in dealing with discomforting situations and the journey towards self-acceptance. The aim was not to prove, but to further explore and advance the viewpoint that women with facial differences have dealt with numerous discriminatory experiences on a daily basis. How then can these women successfully adapt and overcome adversity or personal challenges to find safety and respite was what this study attempted to depict. Since this project intended to learn from the women themselves, the findings presented here would hopefully bring a different perspective on facial differences in order to help increase future awareness on this topic. It attempted to gather the subjective discriminatory experiences of these women to perhaps provide hope, support, and resources for other people who may be coping with a similar life experience.

CHAPTER II

LITERATURE REVIEW

<u>Introduction</u>

The purpose of this qualitative study is to explore and gain more knowledge and insight about the strengths, resiliency, and coping mechanisms women with facial differences have used to deal with discrimination based on appearances. Although a fair amount of research has been published in the area of facial differences, there are still relatively few studies done that focuses solely on the in-depth psychosocial issues that impact women. Due to limitations, the literature review will include an extensive but not exhaustive examination of research related to the topic of facial differences in women.

This chapter investigates and reviews the literature in several areas, beginning with the definition of facial difference, as it is an important term for this paper when referring to individuals of this population. Secondly, the magnitude of the face itself and the important role it plays in human interaction and development will be looked into among those who have a facial problem. The area of discrimination based on appearances will be explored, followed with some of the important psychosocial consequences for individuals in this population. Then, several specific but related social topics such as work, school, and intimacy are addressed. Finally, the topic of treatment options and adaptation as well as a summary of the literature review is incorporated. Since there is a

valuable amount of information related to men's experiences with a facial difference, this data is also being included as studies rarely only focus on female participants. In addition, few researchers have studied in great detail regarding the strengths and positive adaptations that individuals (especially women) with facial differences have made. Therefore, the literature will more frequently investigate one's social, environmental, and personal challenges. However, any areas relating to positive adaptation and healthy coping mechanisms will be included as available.

<u>Definition of Facial Difference</u>

It is not uncommon for individuals with visible differences to be referred to in pejorative or unfavorable terms. In fact, studies show that people who are considered more extreme in their appearances (e.g. disabled, disfigured) are often categorized for their deficits rather than strengths (Cole, 2000). For the purpose of this study, the term 'facial disfigurement' was originally used to describe individuals with any type of facial abnormality (whether from birth or acquired during some life event). For example, one could be born with a congenital facial disfigurement such as a cleft palate, while others could have acquired their disfigurement through an accident (e.g. fire and burns). However, my early exploration on the accessibility of eligible subjects led me to speak to organization leaders dedicated to helping this population, and it was through them that I learned the term 'facial disfigurement' was quite derogatory. Therefore, I felt it was politically relevant and respectful to replace the term 'disfigurement' with 'difference' in regards to this population. Although all the literature and research refers to this population as 'facially disfigured,' I will not be using this term. Instead, what is relevant to this paper and the purpose of using facial difference is the focus on positive strengths,

5

adaptations, and coping mechanisms that women have used to help navigate their social and personal world.

<p style="text-align:center">The Importance of the Face</p>

In order to better understand the uniqueness of the face, it's functions, and the role it plays in society and our inner selves, research suggests that we must first look into the experiences of individuals with facial differences (Cole, 2000; Callahan, 2004). This is because the face is so critical in terms of acting as a visible source of expression for one's inner self and personality (Callahan, 2004). The face not only embodies a large part of our presentation to the world, it is how a person is predominately recognized and later recalled through mental images (Callahan, 2004). In contrast to other body parts (e.g. limbs, torso), the face is capable of extremely intricate and complex fine muscle movements that express moods and emotions (of all intensity), perceptions, self-awareness/reflection, and interactions of all sorts (Van Loey & Van Son, 2003). In previous studies with head and neck cancer patients who had undergone facial changes, many reported a loss of sense of self and negative changes in self-image (Moadel et al., 1998), and studies among patients with reduced facial mobility due to Parkinson's disease also reported a compromised sense of self-worth and limited attractiveness (Cole, 2000). Therefore, some data is indicating that having a facial difference can be extremely challenging, as the face plays the most crucial role in defining ourselves to friends, family, and strangers. The face can also directly affect our interpersonal interactions and may correlate with our social successes or social failures, thus impacting our self-esteem and self-worth (Cole, 2000).

Other research has stressed the importance of the face and it's symbolic value as being cultural and socially defined (Hahn, 1987; Elks, 1990). Dion, Bersheild and Walster's (1972) *What is Beautiful is Good* is an old but important article outlining the existence of an attractiveness bias in society. People who are seen as physically attractive are also seen as socially more desirable, in control, and have other positive qualities attributed to them (e.g. higher intelligence, hold more prestigious jobs). Currently, the attractiveness bias is still highly reinforced in our culture (Elks, 1990), and certain physical characteristics are consistently regarded as positive and desirable while other different characteristics are associated with more negative connotations. These differences may include but are not limited to race, gender, disability, and disfigurement. The media also plays a big role in shaping people's attitudes towards personal appearance, which works against those with visible disabilities and devalues facial differences (Cole, 2000; Hahn, 1987). Hence, people with facial differences may experience facial prejudice (Cole, 2000), or discrimination based on appearance in multiple areas of society.

<div align="center">Discrimination of Women with Facial Differences</div>

The literature on facial differences indicates that the majority of individuals in this population have difficulty with social interactions because they do not feel accepted or comfortable in public situations (Clarke, 1999; Kleve et al., 2002; Papdopoulos et al., 2000). This mainly occurs because one is likely to feel anxious and fearful of what other people's reactions or responses to their facial difference may be, particularly in social spaces where appearance is more valued and emphasized (Hawkesworth, 2001; Papdopoulos et al., 2000). It is especially difficult for women with facial abnormalities

<div align="center">7</div>

because Western ideals have put so much emphasis on appearance and attractiveness that women are under constant scrutiny when it comes to their looks (Benrud-Larson et al., 2003; Griffin & Langlois, 2006). These socially constructed ideals associated with women's attractiveness and the negativity bias can be especially problematic in our society. Women with facial differences are at an extreme disadvantage (compared to non-disfigured individuals) in numerous situations including personal, professional, social, psychological, and political settings. Furthermore, treatment, awareness, and understanding of underprivileged women's issues have often been ignored or underrepresented in our society, so policies and programs regarding discrimination based on facial differences have not been sufficiently addressed (Griffin & Langlois, 2006; Hawkesworth, 2001). It is important to consider that women with facial differences may experience many forms of discrimination on a daily basis. Since there is a significant lack of education and awareness to the general public about the conduct and interpersonal aspects towards people with facial differences (Kent, 2000; Frances, 2000), these problems may remain unresolved and women will continue to be subjected to unfair treatment.

The stigmatization of facially different individuals and the internalization of that stigma remains a common theme in people with facial differences (Lawrence et al., 2006; Newell & Marks, 2000). For example, research has found that enacted stigma and felt stigma seemed to be common (Kent & Keohane, 2001), which also related to increased social anxiety and the development of phobias (Newell & Marks, 2000). This is not surprising considering the consistent unpleasant daily encounters that facially different people come across, including staring, derogatory remarks, avoidance, fear, and disgust.

Particularly in today's appearance conscious society, acts of discrimination against those who are visibly different may be more covert than in the past. It is important to consider that people amongst this population already feel vulnerable and are sensitive to other's reactions, and this combination along with a negative self-image and lack of confidence may lead to feelings of shame, anger, and hopelessness. Individuals with facial differences also suffer from low self-esteem, self-consciousness, and a feeling of worthlessness (Fauerbach et al., 2002; Papdopoulos et al., 2000).

Another problem with discrimination of people with facial differences is that there is a general lack of awareness and advocacy around this topic. For example, there are relatively few role models, media personnel, and public figures with facial differences that could potentially bring more awareness to the community (Clarke, 1999). In most cases, unless an individual or organization comes into direct contact with a person with a facial difference, then there is little responsiveness and motivation to address and enhance one's understanding of the issue. This leads me to conclude that the majority of people receiving any types of intervention are those with a facial difference themselves and their close network of friends and family. However, this not only leaves the problem of discrimination wide open and unexplored for people without some type of facial difference, it also minimizes and hides the expression of true feelings and experiences that this underrepresented population may endure.

The Psycho-Social Impact of Having a Facial Difference

Based on early observation and study, McGregor (1953) was one of the first researchers to have perhaps best predicted that facially different individuals discovered early on that they were socially inferior, and were assigned a marginal/minority status in

society. The opportunities that were made available to the general public may often be denied for this population, and relationships/friendships as well as a variety of cultural activities were likely to be affected or altered in some manner.

In the past twenty years, interest in the psychosocial consequences from congenital and acquired facial differences has increased and become more publicized in research (Callahan, 2004; Dropkin et al., 2003, Rumsey & Partridge, 1994). It is disheartening to note that earlier hospital patients whom were treated for disfiguring conditions, such as burns and skin diseases, were not systematically or routinely screened for risk of psychological distress (Martin & Newell, 2005). Similarly, patients recovering from reconstructive surgery were given little resources to help cope with adjustment or treatment options for managing psychological distress (Van Loey & Van Son, 2003). As a result, many people with facial differences, especially women, suffered from low self-esteem, poor body image, extreme self-consciousness, anxiety, embarrassment, and internalized negative beliefs (Dropkin et al., 2003). These beliefs then may be expressed through behaviors such as an avoidance of social interaction and difficulty meeting new people and making friends (Dropkin et al., 2003; Leoy & Son, 2003; Rumsey & Partridge, 1994). In addition, it has been observed that women with facial differences are likely to be at an elevated risk for psychological disturbance, specifically a higher level of anxiety and depression (Newell, 2000). Furthermore, this population may also be at high risk of psychological morbidity in terms of social phobia due to the constant negative evaluations of daily encounters in one's environment (Newell & Clarke, 2000).

One of the main detrimental effects of social phobia and other social problems reported by individuals with facial differences is isolation and an inability to regain social

currency due to the fear of rejection (Callahan, 2004; Cole, 2000; Partridge, 1990). Many

women with facial differences report they are reluctant to go out in public due to the

staring and rude remarks they may receive (Elks, 1990). Other common responses

include being avoided in public areas, blatant staring, startled reactions, rude remarks,

and uncomfortable personal questions (Elks, 1990; Van Loey & Van Son, 2003).

Empirical evidence has documented that participant's perceptions of avoidance towards

them based on their appearance is likely to be correct, however, other responses besides

avoidance have not always been accurately perceived by people with facial differences

(Van Loey & Van Son, 2003). This is significant because individuals with facial

differences may perceive social interactions differently and in a more distrustful manner

than intended by others. Once again, these cognitive distortions are internalized and

accumulate over time, making it even more difficult to socialize in a healthy manner.

Additionally, these negative thoughts may lead an individual to further isolation, and the

loss of social networks as well as a decrease in self-confidence and self-esteem.

Therefore, it is important to find ways to change negative thought patterns and

perceptions before they become too severe or affect a person's ability to function and live

a normal life.

In the real world, confidence may be built by the ability to trust that others will

validate our self and help enhance our self-esteem (Cole, 2000). However, the

development of confidence is really difficult for women with facial differences because

they are often perceived as unattractive, boring, unsociable, and withdrawn (Cole, 2000).

Soon, these women start to believe that they do possess all these negative attributes and it

may then become a self-fulfilling prophecy (Cole, 2000). This leads to shame and further

isolation, and possibly the development of social phobia or depression along with a high level of anxiety (Newell & Clarke, 2000). Cole (2000) uses the acronym SCARED to discuss the complex mixture of feelings, thoughts, and behaviors that people with facial differences may experience. SCARED decently summarizes the experiences of individuals with facial differences and stands for self-consciousness, conspicuousness, anxiousness, rejection, embarrassment, and difference.

Research has supported the theory that people with visible physical differences tend to have difficulty interacting and relating to other people in fear of rejection, shame, and embarrassment (Callahan, 2004; Rumsey & Partridge, 1994). Unfortunately, the negative consequences of having a facial difference not only affect a person's psychological well being, they also can impact critical areas such as work, school, and intimacy.

<div align="center">Work Setting</div>

Research has often shown the advantages of physical attractiveness in areas like work, as these individuals are not only more likely to be hired, they are also seen as having higher social skills and a greater likelihood for success in life (Elks, 1990; Stevenage & McKay, 1999). It was only in the past few years that research was done about the possible disadvantages of facial differences in the institutional setting, specifically the work environment (Stevenage & McKay, 1999). The conclusions were quite disturbing, with an overwhelming negative bias towards facially different individuals in the recruitment setting. Results indicated that recruiters were much less likely to hire a facially different applicant (port-wine stain) than an applicant with a physical disability (wheelchair). In addition, applicants with both a physical disability

and a facial difference (having both a port-wine stain and being in a wheelchair) were least likely to be hired (Stevenage & McKay, 1999). There was also a significant marked negative perception of applicants with facial differences in terms of both personal qualities and job skills that were not perceived with disabled clients (Stevenage & McKay, 1999). Obviously, these findings contradict the law against discrimination in policies regarding hiring (America with Disabilities Act, 1990), but little is currently being done to address the issue.

The interesting aspect about Stevenage & McKay's study (1999) was that most of the participants with facial differences perceived not just the interview portion to be biased, but the whole recruitment process was seen as unpleasant. For example, this included not being greeted by the receptionist, discomfort while sitting in the waiting room, and encountering other workers when leaving the building. This may show that even indirect interactions in certain social situations may strongly impact an individual's perceptions and experiences with others if they have a facial difference. It is important to gain further insight about a person's discernment of discriminatory experiences, no matter how slight or concealed they may be for the general population to recognize. Also, gender differences were not examined in this study done by Stevenage & McKay (1999), so women's experiences regarding work and recruitment have not yet sufficiently been explored in great detail.

<p align="center">Intimacy</p>

Current research on facial differences has also rarely addressed the issue of sexual intimacy and relationships (Hawkesworth, 2001). There is little empirical evidence and research published around this issue, although suspicions about sexual dysfunction

have been among health professionals for quite some time (Van Loey & Van Son, 2003). This may be due to the researcher's own biases around disfigurement and intimacy, or it may be considered too private or uncomfortable of a topic to study. Also, it is possible that patients avoid complaining about intimacy related problems to their health professionals due to shyness and embarrassment (Van Loey & Van Son, 2003). I speculate that this is more prevalent amongst women, as feelings and attitudes towards sexuality and sexual expression may still be viewed as immoral and taboo (Griffin & Langlois, 2006; Hawkesworth, 2001).

However, I do feel the lack of awareness about facial differences in general may partially be responsible for creating and maintaining negative ideas and perceptions around intimacy with this population. Similar to misconceptions about people with physical disabilities, women with facial differences are often viewed as incapable of having intimate relationships or being physically desirable and attractive (Griffin & Langlois, 2006; Hawkesworth, 2001). Some of the devastating effects of these discriminatory beliefs include the negative impact it has on women's self-esteem and self-image, as well as a sense of hopelessness about being able to find a partner who is willing to accept their facial difference (MacGregor, 1979). More so, these internalized views also impacts a person's willingness to interact with others in social situations, and relationships in general can be extremely difficult and a cause of distress (Bernad-Larson et al., 2003; Lawrence et al., 2006).

In one study with head and neck burn patients, it was reported that disfiguring scars may affect sexuality in that a negative alteration in appearance may impact one's body image and self-esteem, both of which are important factors in sexual life (Van Loey

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& Van Son, 2003). It was also found that sexual satisfaction among women was affected by physical dysfunction as well as body image (Van Loey & Van Son, 2003). Brooking & Bull (1984) did a very early and interesting study on how marriage affected whether a disfigured person would be considered physically attractive or not. Participants were asked to evaluate a photo of a couple where one spouse had a facial difference while the other did not. The fascinating results showed that when a spouse with a facial difference was associated through marriage with someone without any facial differences, they were not perceived in a negative manner. These results contradict earlier studies, which have consistently supported the theory that "what is beautiful is good" (Dion et al., 1972). For example, Bar-Tal & Saxe (1976) had students evaluate pictures of married couples who were either similar or dissimilar in attractiveness. The results indicated a significant gender bias, in that women were evaluated independently while men were evaluated based on their relation to their wife's attractiveness (Brooking & Bull, 1984; Bar-Tal & Sax, 1976). Therefore, unattractive males married to attractive females were evaluated highly on many characteristics but not vice versa. Likewise, one may suggest that in Brooking and Bull's study (1983), perceptions of the facially different spouse may not have been as negatively influenced due to a belief that this person has achieved and overcome tremendous adversity and prejudice in society to be in this relationship. In fact, it is likely assumed that this individual has incredible social skills and achievement because he/she is married to a person without a facial difference. However, this theory is quite uncomplimentary and focuses on the assumption that facially different individuals are somehow only considered worthy of respect and love if they can manage to find a spouse that may overlook their physical appearance.

However, the conflicting results from both studies are important as they may demonstrate how gender may affect a relationship if one partner has a facial difference. In addition, research about relationships and intimacy may help broaden our understanding of ways to help treat and development interventions to assist individuals regarding this sensitive but important topic. Currently, availability and knowledge regarding sexual help for individuals with facial differences is quite limited, and only includes sexual health promotion and sexual counseling to help reduce sexual problems.

Treatment

One area that has created interest among researchers is using cognitive behavioral therapy as the main form of treatment to help individuals cope with their facial differences and handle general social situations in a more positive manner (Clarke, 1999; Kleve et al., 2002). Treatment strongly recommends including social skills training and psycho-education as well as group work to help people gradually adapt and live with their different faces (Partridge, 1994; Robinson et al., 1996). One of the earliest programs designed to offer direct help regarding the psychosocial aspects of living with a visible difference of the face was Changing Faces (Partridge, 1994). This non-profit organization has been very influential in the field of facial difference awareness and treatment, as similar non-profit programs such as AboutFace and Outlook have developed later on and seemed strongly influenced by Changing Faces (Clarke, 1999; Kent & Keohane, 2001; Kleve et al., 2002). James Partridge, an undergraduate at Oxford who was badly burned in a car crash, started Changing Faces in 1994. Partridge survived the traumatic crash and as he began the slow and tortuous road towards recovery, he realized that although his physical health was well looked after, he received little advice or psychological

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support during his aftercare. His face was not only badly scared due to multiple plastic

surgeries and skin grafts, he had also lost some mobility and function of his mouth and

nose area. Partridge felt that one of the most challenging aspects of living with a facial

difference was regaining social entry into the world, and knowing how to handle the

uncomfortable daily encounters with people in public. He wrote the book *Changing*

Faces (1990; 1994), as a tool to help people come to terms with their changed face and

how to restart their lives.

In 1994, Nichola Rumsey (a health psychologist) and Partridge worked

together professionally to create Changing Faces to help those with facial problems. They

also introduced the idea that having social skills (to help cope) was the most important

aspect of recovery from social phobia (Partridge, 1997; Robinson et al., 1996). Like

many current treatment options, Rumsey and Partridge first introduced workshops and

individual counseling to help facially different individuals in need of support and distress

management. For example, it was encouraged during workshops that members focused

on their bad experiences, talk about them in front of strangers in a new place away from

home, and address their fears of rejection, discomfort, and anxiety in public (Partridge,

1994; Robinson et al., 1996). Once people's protective pretenses were stripped away,

Changing Faces helped individuals regain social currency, including ideas about taking

the initiative, gaining control, and meeting new people. The acronym often used during

workshops was REACH OUT, as it stood for reassurance, energy, assertiveness, courage,

humor, otherness, understanding, and tolerance (Cole, 2000; Partridge, 1994). Facially

different individuals needed reassurance that they were not passive victims, and could

regain a sense of control and strength in their social and personal environment. Other

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important social skills strategies, such as demonstrating ways to begin and end a conversation, and building and maintaining relationships with new/old people were also practiced and reinforced (Partridge, 1994). Since dealing with embarrassing and uncomfortable social situations in public was also often encountered on a daily basis, organizations like Changing Faces focused on exploring and rehearsing specific coping strategies for handling such instances with humor and confidence (Partridge, 1994; Robinson et al., 1996). Changing Faces, AboutFace, and Outlook all currently use workshops, cognitive behavioral therapy, and psychomotor techniques to enhance self-esteem, self-confidence, and body image.

In general, workshops that include social skills training and strategies for coping have been shown to reduce social anxiety, as well as self-help leaflets and groups (Clarke, 1999; Kent & Keohane, 2001; Partridge, 1994; Van Loey & Van Son, 2003). Particularly, psycho-educational groups have been successful at reaching out to isolated or fearful people who have become this way due to their changed appearance (Callahan, 2004). In addition, resources for children about bullying and self-advocacy have also served beneficial in the school setting (Cole, 2000; Frances, 2000).

<div align="center">Adaptation</div>

The actual adjustment process and responsiveness to treatment may be affected by many variables, including individual coping style, social support, and personality traits both pre and post injury (Van Loey & Van Son, 2003). Studies have shown that high levels of emotion-focused coping and low levels of acceptance coping correlate with PTSD symptoms and general emotional distress (Callahan, 2004; Van Loey & Van Son, 2003). Avoidance and having a lower quality of life are also associated with emotion-

focused coping (Van Loey & Van Son, 2003). Interestingly, it was found that women used emotion-focused coping more often than men, and successful coping was found to be positively related to the personality dimensions of extraversion, optimism, self-mastery, and hope (Van Loey & Van Son, 2003). It was found that good problem solving skills and the ability to seek emotional support increased one's quality of life, as did other problem oriented coping styles (Callahan, 2004; Van Loey & Van Son, 20003). Critical indicators of recovery according to the Disfigurement/Dysfunction Scale (Dropkin et al., 1983) indicates that self care and interaction with family and friends are important for healing and the level of adjustment, adaptation, or maladjustment in patients (Callahan, 2004).

In terms of social support as an important part of treatment, Patterson et al (2003) found that social support was positively related to self-esteem, positive body image, and life satisfaction among patients with severe facial burns. Cash & Grant (1995) developed a cognitive behavioral model to help with body image problems that may be applied to individuals with facial differences. The model helped change body image schemas, and when tested out among patients with Vitiligo (a condition that causes loss of pigmentation in skin), results indicated significant improvements in one's quality of life, self-esteem, body image, and negative thoughts (Cash & Grant, 1995).

Therapists who work with facially different individuals should examine the client's perceptions, areas of struggle, coping strengths, and problem solving abilities (Callahan 2004). Furthermore, therapists must be willing to listen and effectively manage their own countertransference, as clients have often been avoided or shunned in the past and may currently be cautious and distrustful of others due to their appearance and

presentation (Callahan, 2004; Cole, 2001; Van Loey & Van Son, 2003). Some research suggests that the key to adaptation and development of helpful strategies is empowerment, and the confrontation of one's worst fears and gradually dealing with them with through exposure to the fearful situations paired with social and emotional support (Callahan, 2004). This method may also help clients develop empathy for others who may be experiencing similar situations, and creates a mindset that is better able to relate and communicate.

Another helpful but much needed area of research and advocacy is community interventions for people with facial differences. It has been suspected that the population who mainly utilizes services (e.g. AboutFace and Changing Faces) are families of individuals with facial differences, those with facial differences themselves, and certain professionals (Clarke, 1999; Kleve et al., 2002). It is significant to also recognize that school curriculums and educational awareness programs do not usually consist of addressing or providing adequate support for students with facial differences (Frances, 2000). In fact, programs such as Changing Faces School Service found that the teachers and staff members knew relatively little or no information about how to effectively work with a pupil with a facial difference. Yet, programs such as Changing Faces School Service are not considered a mandatory part of training in most school systems (Frances, 2000). The Changing Faces's school re-entry program aimed at altering negative pre-existing attitudes and knowledge regarding facial differences was shown to be beneficial and of interest to school staff members when used (Frances, 2000). Consequently, these programs along with additional educational resources should be seriously considered and implemented in all school systems to help both children and adults.

Although it is critical to realize that support groups and psychoeducational

programs such as Changing Faces, About Face, and Outlook have all been shown to be

effective in helping people with facial differences (Clarke, 1999; Kent & Keohane, 2001;

Kleve et al., 2002), it is still possible that not enough information is known about the

subjective experiences and goals pertaining to individuals with facial problems.

Researchers have mainly focused on quantitative studies regarding anxiety, social

withdrawal, self-esteem, self-image, work-related difficulties, and the outcome of

treatment plans (Clarke, 1999; Kleve et al., 2002; Lawrence et al., 2006; Newell &

Marks, 2000; Papdopoulos et al., 2000). Although these studies provide valuable

information and important contributions in better helping patients with facial differences,

they lack the in-depth exploration and detailed descriptions to further understand the

experiences of women with facial differences. The majority of these designs measure a

patient's experience using some type of survey or scale (e.g. Fear Questionnaire Problem)

and based on these answers, results are drawn, conclusions are made, and future areas of

research are recommended or implemented. For example, the 12 items General Health

Questionnaire (GHQ-12) was said to be effective in measuring psychological distress in

all clinical populations. However, studies have shown that the questionnaire was not a

reliable unitary measure of psychological distress with individuals with facial differences

(Martin & Newell, 2005). Even though it is important to recognize that quantitative

studies have paved the way for future research and awareness on facial differences, it

might not be the most all-encompassing method of research as each participant's

experience may be distinct. Conclusions that are drawn from quantitative studies are not

specific to individual opinions or evaluations; instead, they are more generalized and give less of an in depth personal understanding of people's experiences.

Also, surveys or scales have a tendency of limiting the fluidity in responses, perhaps leading to important information or insight that may be missed. The research that has previously been done does not pay particular attention to gender differences, and identifying the more specific experiences of women would be insightful and useful when comparing possible future qualitative studies with men. Qualitative results may also be helpful in designing more gender specific treatment programs that are better matched to a particular population's needs (in this case, women with facial differences).

<div align="center">Summary of Literature Review</div>

This current papers aims to explore and depict to the best of my ability adult women's strengths, adaptations, and positive coping methods to manage discrimination and social difficulties due to a facial difference. A qualitative study was conducted to further investigate and advance the viewpoint that women with facial differences have to deal with a range of discriminatory experiences on a daily basis (specifically in areas such as social relationships, work, school, and intimacy). As a result, when and how these women can successfully find safety, respite, and resources for coping despite adversity and personal challenges is what is portrayed in this study. Once again, the purpose is not to prove but rather broaden and add to the knowledge already known about women's adaptation, response, and resiliency to facial difference.

In this literature review, certain specific social and interpersonal areas of life are addressed and discussed including social relationships, work, school, and intimacy. The psychosocial consequences have been shown to have a significant impact on the

behaviors and self-image/self-esteem of women with facial differences, and are related to the treatment progress and patterns of adaptation. Women with facial differences experience many disadvantaged social opportunities, as well as emotional and psychological distress. In addition, public awareness and education about facial differences is not particularly publicized or enforced, and this lack of consciousness or understanding becomes problematic because it creates false assumptions, internalized negative beliefs, and discriminatory acts.

Overall, this vulnerable population is highly underrepresented yet remarkably discriminated against in the public domain. It would be beneficial to have additional involvement from the general community to be more motivated and advocate for awareness and positive changes. Before public advocacy and outreach might begin, I believe it is important to first understand in greater depth how women with facial differences feel about themselves and what positive adaptations and coping mechanisms have been helpful. Since this study seeks to learn from the women themselves, the qualitative nature of my research may bring a different dimension and perspective to the topic of facial difference. I sincerely hope that the subjective information gathered from these women will be used to provide support, assistance, and resources for other people who may be coping with a similar life experience.

CHAPTER III

METHODOLOGY

The purpose of this project was to explore and depict the positive and helpful ways in which women with facial differences have dealt with the social difficulties they had encountered in society. This study aimed to further identify and gain additional knowledge and insight about the strengths, resiliency, and coping mechanisms that women with facial differences have used to deal with discrimination based on appearances. Particular emphasis was focused on providing participants with the opportunity to contribute useful strategies that may benefit or support other people in similar circumstances.

Since most studies about facial differences had been quantitative in nature and usually concentrated on issues such as body image, anxiety, and evaluating the effectiveness of certain treatment plans, a qualitative method with an exploratory approach was used for this study. Fourteen participants were interviewed in-depth through direct telephone contact to examine the more subjective and personal accounts of their experiences of living with a facial difference. A structured interview guide that included four main open-ended questions and one optional question was used. Findings were then analyzed qualitatively through selective transcription and thematic analysis. After data collection and analysis were completed, one participant was randomly selected

to win a 20-dollar gift certificate to Borders Book Store and received the gift card by mail.

<center>The Characteristics of the Participants</center>

The goal was to have a maximum of 15 women (a minimum of 12) between the ages of 18-50 to voluntarily participate for this study. Participants needed to have either a congenital facial difference or an acquired facial difference because of some childhood or adult event. The women must also either be in school (full time, part-time), or be employed currently or have been employed during some point in their lives (self employed is ok). The study initially aimed to sample only women with acquired facial differences, but due to a significant lack of participants available in this specific population, it was necessary to broaden sampling to women who were also born with facial differences. Since the degree of severity of the facial difference and how one felt about their appearance could be quite subjective, all women with any type of facial difference that may or may not have already been altered due to surgery were eligible for screening. Participants could also be from any racial or ethnic group, as long as they were able to speak English because no translator was provided.

<center>Recruiting a Sample</center>

Participants were recruited based on availability and snowball sampling. In addition, the researcher had the opportunity of contacting the director of AboutFace, a national non-profit organization dedicated to helping individuals and families with facial differences (this agency and their contact information was found through Internet research on facial differences). The director then graciously volunteered to help recruit participants that had been associated with the agency who may also possibly be interested

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in being a part of this study. Other support-based websites were also contacted in case

more participants were needed.

However, AboutFace was one of the biggest and most well-known online

resources for individuals with facial differences, so their support and assistance was used

first to help recruit participants. The director offered to make the initial contact with any

possible participants who may be interested, since she already knew most of them and

had established a relationship. A copy of the recruitment form (Appendix D) was first

submitted to the director who then sent it through e-mail to women she considered would

be potentially eligible participants. The original plan was to utilize direct-phone calls to

contact possible participants, but e-mail was used instead because it turned out to be a

much quicker and more convenient method of recruitment for the director. The

recruitment form included a brief introductory paragraph about the researcher and the

purpose/nature of the study, as well as my contact e-mail and phone number. It also

inquired whether it would be all right for the researcher to contact any potential

participants soon by telephone, and if so, to provide the director with written permission

through e-mail.

Once participants expressed an interest to the director and gave her permission

for me to contact them, the following plan of action occurred to help the recruitment

process go as smoothly and promptly as possible. A telephone call was made or e-mail

sent to contact potential participants to help further explore the nature of their

participation. It was soon discovered that using e-mail rather than telephone was a much

easier and more efficient way of contact, as participants were located all over the country

and were often not home when called. All women were then screened to see if they fit

the appropriate criteria based on age, presence of facial difference, and whether they are/were in school or work at some point in their lives.

After participants communicated interest following the initial contact and screening process (and fit the criteria), they were provided with the Informed Consent (Appendix B) and a self-stamped envelope through mailing. Two copies of the Informed Consent were mailed so participants could keep one copy for their own records, and the second copy would be returned back to the researcher. Once participants returned a copy of their Informed Consent, the participant and researcher decided on a set time and date that was most convenient for the telephone interview to take place. The researcher then called the participant to conduct the interview as scheduled.

During the recruitment and screening process, a significant effort was made to include a diverse range of participants based on race and nature of facial difference. However, due to the limited availability and small sample size, it was very difficult to fully accomplish this goal. As a result, the vast majority of participants were women with congenital facial differences, in particular participants with a cleft lip and palate.

A total of 19 women were contacted for possible participation in this study. Of the 19 women, 2 mailed back their Informed Consents but did not respond to any further phone calls. One woman had to withdraw for personal reasons, and another woman did not reply within the limited time frame for participation. Therefore, the final sample consisted of 14 participants with facial differences.

<div align="center">Participants</div>

This research study included 14 women participants, 13 had a congenial facial differences and one had an acquired facial difference. The average age of participants

was 34.6 years old (range 25-46 years). The participants (n=11) mainly all identified as Caucasian, while one participant (n=1) identified as Black/Puerto Rican, another (n=1) as Caucasian/Jewish, and another (n=1) as Latino/Caucasian. Of the participants (n=13) with congenital facial differences, the nature of their facial difference varied from cleft lip and palate (n=9), Apert syndrome (n=1), Freeman Sheldon syndrome (n=1), Fibrous Dysplasia (n=1), and Robinow syndrome (n=1). The participant (n=1) with an acquired facial difference had sustained injuries to her nose, mouth, and chin area due to a biking accident when she was 13 years old.

Participants also held various occupations including Health-care worker (n=3), Homemaker (n=2), School employed (n=2), Non-profit (n=2), Advertising/Marketing (n=2), Engineering (n=1), Book keeping (n=1), and Customer care representative (n=1).

Data Collection

The Human Subjects Review Board of Smith College School for Social Work approved the design and implementation of this study (see Appendix A). The Informed Consent letter summarized the nature and purpose of this study and outlined participation details, as well as any possible benefits and risks involved. Participants were first asked a small set of demographic questions including age, race/ethnicity, nature of their facial difference, how many years the participant had lived with the facial difference (this question would not apply to participants with congenital facial differences), and occupation.

A structured interview guide (Appendix C) that listed in outline form the five main topics and issues that would be included throughout the interview process was used to collect data. The same interview guide was applied to each participant, as there was

enough flexibility to explore and adapt to discussions depending on the content of the participant's responses. The interview guide was also used to help better organize and cover the same basic material with each participant, and help reduce biases and inconsistencies. A final pre-test and mock trail of the interview guide with three Smith students was used to help critique and prepare for the actual interview process. The main questions for each of the five subcategories were open-ended, and probes were used when appropriate to help further explore, clarify, or converse during the majority of the interview.

Questions for the interview had been limited to five, to account for the possibility of long and detailed responses in combination with time restraints. Participants answered three general questions that involved separate but interrelated aspects of adaptation from discriminatory experiences, and one question that focused on the overall strengths and adaptive pathways (if any) that have developed from this experience. The last question on intimacy was mentioned at the end of the interview and remained optional due to the private nature of the topic. Participants were told that they were not obligated to answer any questions they did not feel comfortable doing so, and their responses would not have an effect on their value of participation

The direct telephone interviews usually lasted somewhere between 30 to 70 minutes, depending on how much information was shared and discussed. Participants were always given the option of exploring each question until they were finished, and time was relatively flexible during these interviews. Notes were also taken by hand as the interview was tape-recorded to help organize and analyze the data later on.

Data Analysis

Due to the very personal nature of this study, each participant was assigned a number to help keep track of their data while all identifying information was erased or disguised during analysis and note taking. Since interviews were tape-recorded and provided enough sufficient direct evidence for coding, routine transcription was not used in every interview. Instead, selective transcription was done for clarification, review of content, and analysis on a needs basis.

After each tape-recorded interview, the data and notes were then carefully read all the way through and thematically analyzed. Since the interviews all followed structured guidelines, salient themes and characteristics that portrayed the range of experiences were identified while themes and sub themes were pulled together. These themes were then compared, contrasted, and similarities or differences were noted as well as significant patterns and outliers. Any ideas or concepts that were not captured or unexpectedly produced from interviews were also included in the analysis. Finally, quotes from selective transcription were used to further identify and support these impressionist judgments based on the data collected.

CHAPTER IV

FINDINGS

The following chapter incorporates the findings of my study through 14 phone interviews among adult women with facial differences. It was explained to each participant during the beginning of the interview that the focus of my research was to comprehend the positive and advantageous ways in which they have coped, adapted, and understood their strengths through experience. During the beginning of each phone interview conversation, the term 'facial difference' was defined as any visible difference of the face (whether congenital or acquired through some childhood or adult life event). In addition, participants were also told that they would be asked four main open-ended questions with one optional question at the end. The interviews were recorded and conducted in a casual manner, while participants were encouraged to ask questions or take a short break whenever needed.

The interview guide used was structured to include four main categories and one optional category (at the end of the interview) due to the private nature of the question. The outline of the interview guide focused specifically on identifying information, friendships/social experiences, employment/school experiences, positive learning and methods of coping, and intimacy (optional). Participants were asked open-ended questions as often as possible for each category, while prompts were mainly used to help further elaborate, discuss, guide, or clarify one's response.

The findings collected from these interviews will be discussed according to the order in which the questions were presented on the interview guide. Therefore, this chapter will begin with identifying information, followed by friendships/social experiences, employment, school, positive learning and methods of coping, and finally intimacy.

<div align="center">Identifying Information</div>

Participants

As previously noted, 14 women (n=14) between the ages of 18-50 participated in this study. The average age of participants was 34.6 years old (range 25 to 46 years). The vast majority of women (n=11) identified as Caucasian, while one woman (n=1) identified as Caucasian/Jewish, another woman (n=1) as Black/Puerto Rican, and finally one woman (n=1) identified as Latino/Caucasian. According to the nature of the participant's facial difference, it is significant to note that 13 women had congenital facial difference (n=13) while only one woman had an acquired facial difference (n=1).

Within the 13 women with congenital facial differences, an overwhelmingly large portion of participants had cleft palates (n=9). The remaining number of participants with other congenital facial differences included the following: Apert syndrome (n=1), Freeman-Sheldon syndrome (n=1), Fibrous Dysplasia (n=1), and Robinow syndrome (n=1). The only participant whose facial difference had been acquired was involved a biking incident, as she sustained unsightly injuries to her nose, mouth, and chin area. Since she had an acquired facial difference, the question regarding the years she had lived with this facial difference was applicable. The answer to that was 31 years, as the accident happened when she was 15.

Finally, participants were asked to identify their occupation, as they would later be asked more regarding their employment experiences. The range of occupations was vast, as participants were involved in numerous different fields of work. Therefore, employment has been organized into several categories that may best classify each job description: Health-care worker (n=3), Homemaker (n=2), School employed (n=2), Non-profit (n=2), Advertising/Marketing (n=2), Engineering (n=1), Book keeping (n=1), and Customer care representative (n=1). All participants were also currently living in the United States.

<u>Friendships/Social Experiences</u>

Participants for this second question were mainly asked to discuss their experiences with social relationships including friends, family, community, and new people/places. Once again, the prompting questions were open-ended and additional questions were asked depending on the direction and clarity of each response. Participants always had the option of providing as much or as little information as they were comfortable with. In this section, Participants were invited to share their perspectives and understanding of their experiences around family and friends. Also, participants were asked to consider and talk about a social situation that they would likely feel most comfortable in, and a social situation that would present as most challenging.

<u>Family</u>

In response to the first part of the question regarding family, a significant amount of participants felt that close family (and friends) were a vital and important aspect of their social support system. The general consensus regarding family seemed to be that from an early age, caregivers were sensitive and receptive to not treating them as

"handicap" individuals. In other words, their immediate families were respectful and encouraged them to pursue their interests without feeling hindered by their facial difference. Furthermore, most participants felt that their family provided a steady source of safety, comfort, and happiness that contributed to their current outlook on life. Therefore, it was shown that those who felt they received adequate affection, empathy, and care from their families seemed to feel less introverted and more positive about new social experiences and being around other people.

Although the general responses about family seemed to mainly center on what was previously noted by participants, there were a few women whom did not feel their families played such a positive role in helping them cope with their facial difference. Some participants remembered feeling "like I was the only one who looked like this" or "my parents tried to fix me." It was primarily understood by participants that perhaps their families were not completely comfortable or ready to help them deal with the difficult and challenging aspects of living with a facial difference. Family members may often be "over-protective because there were no other children or adults with facial differences in my community." Even though many women recalled that their families were trying to be helpful and supportive, they still perceived themselves as being different and would often feel insecure and shy around others.

One unexpected aspect about the findings was the discussion around reconstructive surgery during the family/social experiences portion. Although the interview guide never specifically addressed the subject of surgery, almost all the participants brought this to my attention during their responses. The main reaction received regarding surgical treatment for facial differences alluded to the idea that it was

both a beneficial and positive step towards helping them function as well as build a

positive self-concept/image. One participant with a unilateral cleft lip and palate stated, "I

had the Rhinoplasty at age 14, which I think helped a lot with my self-confidence."

Another participant also found surgery to be beneficial in terms of dealing with other peer

members:

> During the summer of eighth grade I had major reconstructive work, and that created
> a big difference. Like before I was teased a lot for my differences and speech, but
> when I went back to school after surgery some of the teasing had stopped.

In general, many of the participants had multiple surgeries (most starting in childhood

and maybe continuing onto adolescence or early adulthood) and felt that with each

procedure, their self-image may have improved somewhat as they felt more confident

about their facial features. During the interviews, all women who were born with a

unilateral or bilateral cleft palate had had at least one surgery performed, and it seemed as

if they were perhaps the most satisfied with the outcome of their reconstructive work

(compared to participants who did not have a cleft palate).

Friends

In terms of experiences with friendships, participants defined that there was a

significant difference between "real" friends and acquaintances. Real friends were

basically defined as people whom you have known for a long time who do not judge you

for your appearances but rather your personality. One woman felt that a real friend was

"someone that you feel a deep level of trust for and understanding with, and you have

known them for a long time and are able to talk about anything." Most participants

agreed that in their personal lives, they would only consider a few people (ranging from

1-4 members) outside of their family to be real friends. For example, one woman with a

cleft palate explained her feelings about true friendships and the characteristics that may

define a real friend compared to an acquaintance:

> I guess you know....I've always had a few select group of people who are just very good dear friends and I still have them. And I make friends easily, but I regard most friends as acquaintances and not [real] friends. There's only a small group that I would regard in the real friend category…..I feel I have a high level of comfort [with real friends] in what I'm willing to talk about and trust that what I talk about won't be used against me in some way and or repeated….that sort of thing.

Typically, participants felt that the people they encountered on a daily basis (e.g.

work, school, social events, etc) were not considered real friends but rather

acquaintances. This was because friendships took time and effort to build, as the level of

trust and being able to look past their facial differences was critical in fostering any close

relationships to flourish.

When asked about when and how these real friendships had developed, an

astonishing number of participants stated that they're closest and best friends were

actually from elementary school or early childhood. Many said that they first became

friends with these individuals during first or second grade, and had since remained

extremely close with one another. One woman mentioned that "best friends can go

through anything, two of my closest friends are still from childhood." Although distance

may have physically separated some of these friends over time, they currently seemed

nonetheless just as loyal and supportive to participants as friendships that were developed

in adulthood. In addition, many of these early childhood best friends played a critical role

in the level of social support and belonging they felt in school. A woman with Apert

syndrome recalled "when boys teased me [in school], I felt lucky because I had a group

of friends to turn to." Similarly, a number of other participants also remembered being

teased or meanly treated by peers at times, but they knew that they could always depend on their true friends for comfort and safety. Therefore, this encouragement and compassion that was offered by their friends provided a steady amount of support that was advantageous and appreciated even today.

Most Comfortable and Challenging Social Experience

All participants were asked during the first portion of the interview whether there was a social situation that they felt most at ease in and why. The responses to this question were mostly split into three subgroups, mainly categorized into close friends, family, and neutrality because they currently felt comfortable in all social circumstances. Most participants felt that with close friends or family, they were best able to just be themselves and felt very comfortable because there was no fear of judgment or focus on their facial difference. Especially within the small group of women with facial differences other than a cleft palate, everyone felt that being with a small number of people (ranging from 1 to 4 members) that were either close friends or family was where they felt most content and relaxed. One woman with Freeman Sheldon syndrome said, "I prefer 1 on 1 conversations with close friends, like we can chat and I'm comfortable with that."

For participants who felt neutral, they explained that they could not think of or pinpoint a particular social situation that would be more comfortable compared to other circumstances. For example, one participant with a cleft palate shared how she felt there was not a social situation that she did not feel comfortable in:

I don't like doing certain activities, it's not my cup of tea. But I mean I'm definitely not uncomfortable [in terms of her facial difference]. I just don't think there is a social situation where I'm uncomfortable in.

However, it was noticed that only women who were born with a cleft palate responded with the more neutral stance, while participants with other facial differences mainly provided answers including friends and family. The only participant whose response varied from the above three subgroups was the woman with an acquired facial difference. At the time, she felt "most comfortable being alone because I didn't have to worry about what I looked like." It is worth addressing that this participant had to also deal with the change in her physical appearance, while participants with congenital facial differences did not. This added layer of adjustment was difficult, and may have led to feelings of fear, anger, and loss of identity. Luckily, this participant has had a very successful recovery outcome over the years and currently does not find her scar to be especially bothersome.

Participants were then asked to consider and discuss a social situation that might present to them as most challenging and why. An overwhelming majority of women mentioned that being around people whom they did not know was a difficult process. This was mainly due to the fact that strangers may react negatively or make the situation awkward because of their appearance. One woman said, "I did have the initial anxiety and stress about grocery shopping or events, because you never know how people may respond." Although a negative response may not always occur when meeting new people, many women were still anxious about the staring, whispering, and overt comments made in public. Others felt shy or uncomfortable because they were aware of the importance of appearance and how that may affect first impressions. One Black/Puerto Rican woman

with a unilateral cleft lip and palate talked about her concerns regarding making an impression with others:

> Going to meet new people, those are situations where I'm most uncomfortable. Specifically, going into situations where I have to present myself and make an impression about myself….I'm afraid of what they are going to focus on, like making a first impression.

Therefore, a lot of participants were never quite sure if a stranger would be able to see beyond their facial difference and get to know their personality instead. Included in this category of unfamiliar people were also children, as quite a few women talked about the challenges of hearing and seeing children's inhibited reactions. Also, the teasing and disrespectful remarks made by some strangers were hurtful to their self-confidence and esteem, thus making being in an environment with unfamiliar people one of the most challenging social situations.

<u>Employment</u>

The third question of the interview involved employment, as this issue was further explored by asking participants to briefly characterize their work experiences. Including if there was anything significant during the recruitment process, and their current thoughts and feelings around work in relations to their facial difference.

<u>Recruitment</u>

The general consensus regarding the recruitment process was that having a facial difference produced no significant effects on the hiring procedures during their experience. In fact, the majority of women felt that they themselves probably noticed their imperfections more than their interviewers did. Participants in most cases did not

feel discriminated against due to their facial difference, and perceived the recruitment process to be "fair and reasonably pleasant."

<u>Other Work –Related Experiences</u>

Participants also discussed how they felt about their overall work experience and relations with other professionals. Similar to the recruitment process, the majority of women felt pretty content about the treatment they received from employers and fellow staff members. Within this group, about half the women also believed that their facial difference was advantageous in contributing to a more dedicated work ethic. As one woman with Freeman Sheldon syndrome described, "I worked really hard because I was trying to prove that I was an excellent employee and it felt good to have others recognize my work. That challenge was good." Similarly, many other women have described how they were able to use their past experiences and knowledge gained about living with a facial difference to help others who may be in comparable situations. For example, one woman mentioned, "I used my position as a substitute teacher to talk about people who looked different, it was a teaching tool and has helped me in a lot ways." Other women who have gone into health-care fields or non-profit organizations were also able to rely on their previous experiences of living with a facial difference to help other people.

In addition, due to the frequency of exposure to new environments and social situations, the women in this group felt their professional experiences had somewhat helped them become less anxious around others. Overall, participants expressed that they worked hard to do well in their jobs because it provided a sense of satisfaction and achievement from all their dedication and commitment to their work.

Unlike the positive experiences of the previous group of women, a few participants felt that their position at work was more challenging and had experienced differential treatment based on their physical appearance. These women sometimes felt targeted at work by other employees/employers, or felt that they were seen as less capable in their professional abilities than women without facial differences. For example, one woman talked about her impression of the recruitment process in relation to her facial difference:

> I had an internship and somebody knew me and referred me so I got this job. I have to work a lot harder to get things done than people without facial differences. I've found that I need to know somebody in order to get an interview, and when I go on my own, I have found it to be unsuccessful.

In addition, the same participant elaborated on a specific situation at work where she felt she might have possibly been denied a promotion due to her appearance:

> I haven't been given the opportunity to do more in my job because either somebody whom supposedly is more skilled comes along, or some other excuse comes up for me not being promoted.

For others in this group, working in public (e.g. retail, school) could sometimes be difficult because people may stare, make inappropriate comments, or ask questions that would lead to another explanation about why they had a facial difference. Also, some women within this group felt that during the beginning of their jobs, their co-workers seemed "curious but were never straightforward in talking about their facial difference." This produced a rather awkward dynamic at work, but did seem to dissipate or at least decrease over time. However, most participants would have rather preferred their co-workers to be more forthcoming and respectful rather than avoidant in these situations.

As one participant said, "they could of just asked in a respectable manner and I would have told them the truth."

School

After questions in relation to employment, participants were then asked to talk about their school experiences. Initially, some participants were a little uncertain of which school years they should discuss because the question did not specifically focus on a particular time. So participants were told to talk about any time during school that they felt comfortable sharing, especially if the experience was related and significant to their facial difference. The general topics of discussion for school seemed to center around two subgroups, mainly elementary through high school experiences and social relationships during this time.

Elementary through High School

An overwhelming majority of women (with congenital facial differences) discussed that early adolescence, or Middle School, was the toughest time in terms of adjustment and their social-emotional well-being. As noted earlier in the friendships/social experiences section, many participants recalled that early childhood (kindergarten or elementary school) was when they felt very accepted because many of their peers seemed to not yet recognize certain social differences. One woman recalled that "little kids" (kindergarten through 1st grade) were good, because if you looked different it wasn't torture." Elementary school was also when a large number of participants had developed extremely strong and long-lasting friendships with a few other classmates. Quite a few women talked about how their friends from elementary school

were still some of the people they were closest and most comfortable with currently in life.

The interview responses strongly alluded to the fact that the hardest years for most women were during middle school. The main concerns and reasons for this seemed to center around a dramatic increase in teasing, bullying, and harassment from peers. Comments such as "what the hell is wrong with your face?" or name calling such as "cash register" and "freak" were particularly hurtful. Although a few women within this group felt there were times in elementary school where peers made fun of their facial difference, most women did not believe it was to the extent that it had been during the transition into middle school. Many participants also mentioned that more boys than girls teased them, and often it was the boys that made the harsher and more hurtful comments.

In addition to experiencing a lot more prejudice and mockery during middle school, many women also felt they had internalized many of these negative messages and that affected their self-concept and self-esteem. In one instance, a woman with a unilateral cleft lip and palate remembered being compared to the only other student (a young male) growing up who also had a facial difference:

> We were in the same homeroom through out childhood, and they [other students] would always say we would get married because we looked like freaks. So we avoided each other. It was weird because it was like looking in a mirror and I wondered, did I really look that bad?

As early adolescence was already an awkward and confusing time for most young people, it seemed extra challenging in some cases to also have a facial difference.

Fortunately, High school was a time of positive change and maturity for most of the participants that were interviewed. After middle school, many women commented on

how high school was a much more liberating, and sociable time in terms of their overall experience. A lot of women talked about a decrease in teasing and bullying from peers, and interpreted the change as their fellow classmates maturing and becoming more tolerant of differences. It was during high school that a number of participants within this group felt optimistic and hopeful about belonging into society and feeling accepted by their peers. One woman described that she focused her "energy on science and math as I was very good at it. I also became very active and people became more interested." Another participant commented, "I felt a whole lot better in high school, like maybe I was passing into a society where I may be accepted and known for who I was on the inside."

Many women claimed that during high school, they probably had some of the same concerns as other young women their age without facial differences (e.g. weight, make-up, clothes, etc), and considered it a normal aspect of adolescence. An interesting concept that was mentioned several times by women in this group was how cosmetic surgery had helped them cope and deal with the stressors surrounding appearance in school. Many participants noticed that if the outcome of the surgery were good, they would receive less negative attention towards their facial difference, and at times positive reactions. A woman with a unilateral cleft palate said, "After I had most of my surgeries and my facial difference was less noticeable, I felt my body image started to improve and things became easier." Therefore, surgery seemed to have helped several women feel more "normal" and accepted during their childhood and adolescent years in school.

In contrast to the previous responses, there was one participant with Robinow syndrome that had a considerably disturbing experience in school. This incident stood out

from other participants as it involved a teacher rather than a peer. Unlike the experiences of most participants, she had categorized both her elementary and middle school to be difficult and unpleasant. During first grade, she was actually bullied and harassed by her teacher who exposed and targeted her as being "disfigured." She remembered that her teacher would make indirect comments about her syndrome (a rare condition that affects the growth of her facial bone structure), and also hit her knuckles when she answered a question wrong. Due to the treatment she received from her teacher, she remembered feeling quite traumatized by the whole experience. Eventually, her parents intervened and a new teacher replaced her old instructor. Her new teacher did not treat her as "different," and the participant really appreciated the fact that she was no longer subjected to feeling singled out from the rest of her classmates:

> I was told that I was just like anyone else and could do anything I wanted to. This reinforced my self-worth, and although it did not shield me from the teasing, I learned to navigate through things my own way.

This woman felt that by allowing no special treatment in school, she was given the valuable opportunity to explore and resolve her own problems. She knew that there would always be others who may judge her based on her appearance, but she felt more confident of handling these situations by experiencing life as a regular child.

Social Relationships in School

The area of social relationships was the other main issue that arose when participants spoke about school-related experiences. Within this group, women specifically mentioned friends and the importance of peer support, as well as concerns and curiosity regarding boys and dating during adolescence. The majority of women mentioned that even although they were not "popular," their small group of close-net

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friends played an important role in sustaining their self-esteem and comfort level at school. Having at least one good friend at school offered a "sense of emotional security and support," especially around teasing or bullying from other schoolmates. One woman had this to say about her childhood friends, "these people protected me from others who tried to hurt."

As most participants grew older and entered into puberty, they inevitably became increasingly interested and curious about attraction and relationships. Similar to their peers, they would often think about their developing "crushes" and talk amongst their friends about boys. However, there were some similarities and differences between participants with cleft palates versus participants with other facial differences.

The most common concern among participants with cleft palates had to do with kissing, and being worried about whether they would kiss the "same way as someone without a cleft palate." Surgery to fix the cleft lip and palate also seemed to help one feel more secure about their mouths and ability to kiss "normally." One participant remembered feeling self-conscious and anxious in the beginning about kissing, but later realized that she did not need to worry so much:

> I remember when I first started kissing I was nervous about the fact that I had a scar on my lip and I really didn't have much of an upper lip because of my cleft palate…. and then when I first started french kissing boys, it was like 'oh my god!'….But they never complained so I guess it was all good!

It was certainly not uncommon for women with or without a cleft palate within this group to feel anxious about the way they were viewed by the opposite sex (young males in this case). Many had felt ignored or teased by boys in school, so they were apprehensive about whether people found them attractive and interesting later on in life. Almost all

women interviewed felt dating and relationships were challenging in school, as most participants either did not date or dated only a few times. Some even had disastrous experiences or pushed away those that may have been interested, in fear of rejection or refusing to believe that anyone would want to date them. One woman humorously remembered how she "pushed a lot of guys who were interested away or avoided them, cause she couldn't believe they really found her attractive." Encouragingly, many participants felt that as they matured in age, they were also exposed to more people in numerous environments. This experience has made some women recognize, achieve, and maintain a very successful and enriching relationship that is highly valued and respected.

The final and most prevalent similarity between all groups regarding school was a definite desire to have more psycho-education and contact with people with facial differences. Although this ties into the next section of the interview about positive coping and methods of learning, participants seemed to have wanted teachers and peers to be more sensitive and knowledgeable about respectful treatment of anybody with visible differences. Many women said that their "teachers didn't know a lot about facial differences nor were they required to attend educational/training programs around the issue." Therefore, teachers were usually not equipped to handle the social conflicts or challenges that occurred in the classroom.

Furthermore, an overwhelming number of women said that growing up, they rarely if ever met another person with a facial difference. One woman with a unilateral cleft palate and lip recalled, "I was the only one like me in the entire school." This led to a strong feeling of being vastly different than other children, and at times left memories of isolation and sadness about not fitting in or being accepted by society. In particular,

one woman with Fibrous Dysplasia had so little information and exposure to other people

with similar conditions that she first learned that there were others like her through a

movie:

> At 9 years old, it was really rough thinking I was the only one in the world like me. I didn't know there were other people like me until I was grown. [When asked how she found out that there were other people like her]….Well, it sounds kind of awkward but it was the movie 'Mask.' ……I watched it and was amazed that there was someone else in the world with facial differences.

It was a difficult experience for many women with facial differences growing up because

there were so few psycho-educational programs. Essentially, a lot of participants felt that

it would have also been very valuable to meet other people with facial differences (in a

safe and contained environment), as it would have provided a sense of twinship and

connection with people similar to themselves.

<u>Positive Learning and Methods of Coping</u>

The final question asked participants if they would mind talking about any helpful

or meaningful ways of dealing with a few of the discomforting situations that they had

described in relation to their facial difference. It was explained that one of the main

purposes of my study was to further understand and appreciate the positive adaptations

and coping mechanisms that women have found helpful during times of adversity. It is

perhaps their personal accounts of what has been helpful that may provide a useful source

of strength and hope for other people who may be dealing with similar situations based

on their own facial difference. The powerful responses that were received could primarily

be summarized into four categories: positive acceptance, faith in a higher existence,

community outreach/activism, and being involved in groups with other people with facial

differences.

<u>Positive Acceptance</u>

The concept of positive acceptance was the most common idea that had been recognized as helpful for women in this study. Positive acceptance meant being "content and at peace with one's physical attributes (including both good and bad features), and realizing their inner beauty and self-worth." In general, participants felt that being accepting of themselves and their facial difference was one of the chief paths towards living a happy and fulfilling life. Fully believing and knowing that one is worthy of attention, love, and affection from other people and themselves was in some ways therapeutic, as it helped many women prioritize what they felt was really important in life. What was humbling about their responses was that almost all the participants acknowledged that their level of self-acceptance fell more on a spectrum rather than one particular position. This meant that their self-esteem, confidence, and self-image could fluctuate depending on certain social situations (e.g. bad days). For example, one woman shared, "If I'm having a bad day, then I'll probably cry about it and not feel so great about my body image." However, the important and similar component to most participant's answers was that if they identified as being accepting of their facial difference, then on most days, they loved their bodies and appreciated themselves for the way they were.

Many participants remembered that it was <u>a</u> much more difficult process to fully accept their facial difference during childhood through late adolescence. It was possible that part of their young mindset at the time may have contributed and impacted their self-esteem, self-image, and the development of relationships with others. Therefore, the journey towards self-acceptance and reinforcing the positive attributes rather than the

negative has not always been an easy process for many women. For example, one woman described acceptance as being critical, because "first we must accept ourselves before we can help others accept us."

The uplifting and admirable piece of their stories was that currently, almost all the women that were interviewed felt either fully accepting or at a very high level of acceptance in terms of their facial difference. This meant that overall, they were satisfied and contempt with their physical appearance, and have made a conscious choice to filter out a lot of the negativity that they may encounter. This has helped many women put things into perspective, as they have learned that what is important in life is not how one looks, but rather how one acts and treats other people in society.

Faith

Similar to positive acceptance, many participants felt that faith in a higher existence or being (e.g. God) was a helpful resource in dealing with the difficult social and personal challenges in life. A significant number of participants felt that having faith was a valuable tool in understanding and dealing with their facial difference. For example, one woman with a cleft palate explained how she believed that faith had been a positive source of learning and method of coping:

> Definitely it's my faith in God, and I'm thankful to be born this way because if I hadn't, I would probably not be as sensitive or caring towards other people. I understand that we were all created as beautiful beings and for a reason, it's a beautiful thing.

Having come to terms with her facial difference, this woman appreciated her faith in God because it helped her find meaning associated with her condition. It may have also provided a sense of resolution, as she was able to fully accept herself without resentment

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or anger for why she was born with a facial difference. On a side note, a few other women within this group who also believed faith was an important resource mentioned that surgical procedures and recovery was less frightening (or anxiety provoking) knowing that they could always turn towards a higher existence or being for support.

Activism

For the majority of participants, giving back to the community and helping others had been a successful way of achieving satisfaction and a sense of fulfillment in life. A few examples of community outreach that participants had done included volunteer work at camps, reaching out to families of children with facial differences, and presenting at or attending conventions dedicated to providing facial differences awareness. The women seemed to feel that being active in the community was one of the most meaningful and enriching aspects of their lives. A lot of participants felt they did not receive enough support and educational resources about facial differences growing up, and now are dedicated to advocating and contributing to this area of need. For example, one woman worked in the pediatric field and enjoyed helping children and their families, "I like working with children with facial differences and their families. Patients come to me for advice and to hear my stories, it feels good to be able to offer guidance and a voice." The ability to play a proactive role in helping young people seemed to be extremely gratifying, as most participants agreed that there was currently not enough awareness or work being done to address the many challenges that people with facial differences may encounter. It was also mentioned that in addition to support and outreach for children, there should be more services available for adults, as opportunities like these would benefit people of all ages.

<u>Groups</u>

Participants frequently suggested that joining a community or group with other people who have similar shared experiences was advantageous for women with facial differences. It was recommended because verbally sharing one's stories of experience (both successes and challenges) was helpful in that it could create a potential bond and relationship with others. Many admitted that to really open up and talk about some of the tougher issues was "nerve-racking" at first, but they were glad they had the courage to do so. It was important for all of the women to surround themselves with people who were sensitive, caring, and reinforced their strengths and positive attributes. As one woman cited, "I think it's important to surround yourself with positive people that make you happy and expect good thing out of you."

Having an encouraging point of view and being with positive people may help build a sense of belonging rather than isolation, as group members provided camaraderie and connection in the world. As stated earlier, having a steady social support system through out life seemed to foster a stronger link with other people and a more positive outlook on life and for themselves. Many participants felt that growing up, they did not have the option of attending social support groups or even meeting other children/adults with facial differences. Upon reflection, participants would have greatly appreciated this opportunity to come together and learn about other people with similar struggles and life experiences.

In addition to social support groups, a significant portion of participants would have also wanted some type of social skills training. The training may include but would not be limited to practicing and learning some strategies around dealing with

uncomfortable social situations that one may encounter. Some women also wanted to be able to first rehearse and apply some of these various responses learned in social skills training with their fellow group members. One woman suggested that it would be great to "role play and practice conversations with others, like looking people in the eye and communicating effectively." The group may provide a safe and non-judgmental environment to really practice and feel more confident before testing out these newly learned skills in everyday life. Then afterwards, there could be discussion about the exercises done during social skills group so that members may reflect and express how that experience felt. Therefore, participants proposed that having social support and skills training may be a very useful way of learning how to become more assertive and successful in meeting one's needs despite having a facial difference.

<div align="center">Intimacy</div>

At this time during the interview, all participants were informed that this last question regarding intimacy was completely optional, and would not affect their participation if they did not want to answer. Using the interview guide, the question was first read to all participants, and then everyone was given the option of continuing to talk about their experiences or having the interview conclude without further questions. It was also mentioned that the literature review regarding facial differences included very few findings around the issue of intimacy. Therefore, this question was included at the end of the interview so that if any participants felt comfortable with the subject matter, they would be helping to contribute and broaden the current understanding of intimacy within this group. A surprising 12 participants agreed to discuss the topic of intimacy, and the responses seemed split into two subgroups. The first being women who were currently

very happy and fulfilled in terms of their intimate lives and did not feel their facial

difference had a significant effect on intimacy. While the second subgroup of women felt

that their facial difference played a bigger role, including affecting areas such as body

image, perceived level of attractiveness, and comfort around potential partners.

Facial Difference Not Affecting Intimacy

        Women who responded with a high level of satisfaction and contentment

regarding their intimate lives composed almost half of the responses related to intimacy.

However, it is important to note that all the women who belonged in this subgroup where

either married or involved in a serious relationship (e.g. engaged, dating for many years).

The reason this may be significant was that many of the women mentioned how their

spouse or partner made them feel completely comfortable and attractive, a feeling which

they did not necessarily receive from relationships in the past. Therefore, it may be

possible to speculate that women who were in serious monogamous relationships for this

study felt that their attractiveness and views about intimacy have been positively affected

by their loving partners. For example, one woman with a unilateral cleft lip and palate

described that her husband made their romantic life "terrific" and she felt "completely

comfortable and beautiful with him."

        It is important to identify that within this group, almost half the women felt that

their intimate lives and self-image had changed in a positive way after meeting their

spouses. One woman explained how her trust became so strong with her husband over the

years they've been together:

> I guess my advice would be to not pre-judge your partners, and try to be open and
> honest and don't push anyone away…..Let your heart be open because I have been
> with my husband for twenty-two years, and I met him as a teenager. Before my

husband I only went on double dates…..and at first I was worried about my facial difference and that he was too good to be true. I thought he might feel sorry for me, but slowly I learned to trust him.

Thus, the majority of women in this subgroup related their intimate lives in a positive light, and provided a hopeful outlook on intimate relationships based on their strengths, level of trust, and the amazing role that one person may fulfill in someone's life.

Facial Difference Affecting Intimacy

For women whose feelings regarding intimacy had been impacted by their facial difference, romantic relationships seemed to be challenging in that many women have struggled to find long-term connection with romantic partners. All of the women in this subgroup were not married, but had gone through at least one previous dating experience while some had just begun a new relationship. Also, a few women in this group were involved in long-distance relationships from people they've met online, or through Internet support groups related to facial differences.

The one common aspect that all women shared in this group was that they felt anxious about their facial difference and how others may respond or reciprocate to their feelings of attraction. Also, many participants mentioned that because their strengths were not emphasized very often by peers or reflected in society, they struggled to find positive traits that others may value. One woman with a bilateral cleft palate mentioned how she really wanted to highlight certain positive attributes and went through extreme measures to do so:

> I think for me part of it was related to my cleft palate…..I think I definitely had an image of myself that I wasn't as pretty as the other girls or as attractive….I did know that I was always thin and got a lot of positive feedback about that. So as I got into my teenage years, I remembered being more conscious about my body because it was the one thing that people were always like, 'Oh my gosh, you are so thin. You

can wear anything,' so I wanted to keep that.

As noted earlier in the positive learning and methods of coping question, it was common for a women's body image to fluctuate depending on the circumstances. However, during her battle with an eating disorder, this woman felt that her only positive quality was to remain thin because she believed the rest of her appearance was flawed. Fortunately, through different modalities of treatment such as individual and group therapy, she was able to adopt a healthier body image and a more positive lifestyle.

Through out the last part of this interview, having anxiety and feeling self-conscious were often mentioned, especially if someone had been teased or bullied in the past during school. This might have led to an increased level of worry and concern around the issue of intimacy, thereby affecting one's confidence regarding the opportunities available for meeting someone who may overlook their facial difference and provide enough sensitivity and care for trust to fully develop.

<u>Summary of Findings</u>

The information discussed in this chapter both reflects and characterizes the personal experiences of 14 women with facial differences through direct phone contact using a structured interview guide. The responses mainly demonstrated that even though all the women who participated have encountered life challenges (of various degrees) based on their appearance, most have learned from these experiences and have developed many helpful methods of coping. Specifically, participants commented in detail regarding the knowledge that they have gained through areas such as friends and family, employment, school, and intimacy (optional question).

In addition, the majority of women had an optimistic and positive outlook on life and valued trustworthy friendships and relationships. They believed faith and acceptance were important because they provided a sense of support and rationale for understanding why people were born the way they were, and this helped contribute to many women's own sense of contentment with their appearance. Almost all participants no longer felt the strong desire or need for approval from people in society that they were unfamiliar with or had no relationship to. This was mainly because they were receiving genuine and sufficient support, care, love, and acceptance from the people in their lives who did matter (e.g. close friends, family, and partners). Finally, the majority of participants were open and willing to discuss the aspect of intimacy, and mentioned a variety of thoughts related to their experiences regarding romantic issues and relationships. As the interview came to a close, all 14 women had expressed enthusiasm for having participated in this study to help further deepen and explore the experiences of women with facial differences.

CHAPTER V

DISCUSSION

The purpose of this study was to further understand and learn about the advantageous ways in which women with facial differences have dealt with some of the more challenging aspects of their everyday lives. One of the goals for interviewing participants in depth was to listen, recognize, and appreciate each woman's personal experiences so that it may broaden the general knowledge around facial differences and possibly bring hope for other people in similar circumstances. Upon reflection in this chapter, I will address and evaluate the importance of this research, along with my own learning regarding the accessibility and future implications around this study.

The Importance of Research on Women with Facial Differences

Early on, I learned from both participants and through previous research just how concealed and underrepresented people with facial differences were to the general public. Although it may not be uncommon for anybody to encounter or know someone with a facial difference, the stigma and negative stereotypes that may be associated with people from this population were rarely addressed in either the individual or institutional level. If one is fortunate, then exposure, discussion, and possible social training may be provided for families and friends of individuals with facial differences. However, with little public acknowledgement and understanding of the experiences of those with facial differences, I was passionately interested in finding out some of the ways a person with facial

differences may positively cope, learn, and adapt to their environment. Furthermore, I specifically chose to study women, as they have historically been an underrepresented population, adding gender as another level of discrimination in addition to having a facial difference for participants. The age of participants was narrowed down to adults between 18 and 50 years old, as the interview guide would not fully apply to most participants who were younger or older (due to being in a different life stage) than the required ages. Finally, due to the estimated availability and accessibility of participants, both women with congenital and acquired facial differences were asked to participate in this study.

One unexpected characteristic about participants in this study was the overwhelming number of women with congenital facial differences compared to acquired facial differences. The majority of women were either born with a unilateral or bilateral cleft lip and palate. This sample of women with facial differences was a contrast from the earlier research in the literature review chapter, as the literature review did not focus specifically on any participants with a cleft lip and palate. More studies have been done with people with acquired facial differences (e.g. burns, cancer) and congenital facial conditions other than a cleft lip and palate. Therefore, the findings from this study may not fully encompass, reflect, or apply to the conclusions found in the literature review. The surprising ratio of so many more women with congenital facial differences than acquired was not a prospect that was foreseen, nor was the number of participants with a cleft lip and palate.

Upon evaluation, I believe the focus of my study was both enriching and beneficial to the field of facial differences study in clinical social work. Although the information gathered from my research was limited and only represented a small sample

of the overall experiences of women with facial differences, I do consider it productive and useful in broadening our awareness about the positive adaptive coping mechanisms used by some women. The participants often elaborated in detail about their experiences, and shared ideas about what they have found helpful so that others in need may also take something away from their sincere stories. After the interview, many participants expressed how talking and relating their experiences for the purpose of this study was advantageous to their own sense of self, as it provided an outlet for reflection and possibly growth. Another gain for participants was that they were eager and excited about sharing their knowledge and expertise in order to help other people with facial differences. This opportunity was highly valued because of the lack of awareness and education regarding facial differences for the public, so being able to contribute and inform others in a helpful manner was perhaps the most fulfilling aspect of being in this study.

<p align="center">Women with Facial Differences As An Open Topic of Study</p>

As mentioned earlier, the availability and accessibility of recruiting women with facial differences as participants in a qualitative research study was a concern. However, I have found women with facial differences to be a population that is open to current research, and can indeed be studied in depth. I have also recognized that one helpful way to find possible participants and more information about recruitment is to contact someone who is already involved in working with people in this population. For example, contacting a director of a non-profit organization dedicated to working with people with facial differences may be a useful way to begin the process, as it may be critical to first find out where and how participants may be recruited. In this case, there are several

online Internet support organizations for families and people with facial differences. Therefore, I was able to make the appropriate contacts and receive guidance and information about participant recruitment. I have found that when recruiting participants for qualitative studies of sensitive issues, it may be beneficial for your contact person to first introduce you (e.g. over telephone or through e-mail) and your research study purpose to any possible participants. This helps create a less alien and more familiar introduction as both you and any interested participants would at least know one mutual person in the process. Also, researchers should not expect people to immediately trust you or convey great interest in your study, so having your contact person who already knows your population may help open doors for a more successful recruitment.

Once participants have expressed interest, it has been my experience that using e-mail (or brief phone conversation) is the best way to keep in touch and set up an interview time. Keeping conversations friendly, casual, and at time humorous may help create a more relaxing atmosphere during the actual interview. Participants should also be encouraged to ask questions or take breaks when needed. I have found that using direct over the telephone interviews (as participants were located all over the United States) along with a few open-ended questions followed by prompts or probes (when necessary) seemed helpful. Participants were given the freedom to provide as much information as they felt comfortable doing so, but were not limited to answering questions that were specific or broad. The categories selected for the interview guide were based upon the literature review in hopes of adding to or further developing understanding of a few significant areas of life that may impact these women on a daily basis.

Central to this study was the shifting of focus from negative experiences to recognizing and elaborating the positive adaptations and methods of learning that had occurred for the women. Although participants were inevitably going to recall negative experiences and memories, this information was more often used to build on what participants have learned and used from these experiences to presently tolerate any challenging aspects of their lives (related to their facial difference). I believe working with participants from a strengths perspective rather than a deficient point of view was helpful. For example, my contact person suggested using the term 'facial difference' rather than 'facial disfigurement,' as the first term proved much less pejorative and concentrated more on a person's strengths and individuality. It was also remarkable to hear how satisfied and confident many of these women were about themselves currently, and how they attained that high level of self-acceptance and was something I wanted to highlight and identify in this project.

Overall, the study mostly likely provided participants with the opportunity to educate and possibly reach out to other people (especially women) in similar situations. In my opinion, the need for this kind of outreach, awareness, and community activism is apparent and needed in our society. Although learning and exploring the discriminatory experiences of disadvantaged populations is vital in deepening our understanding of people with facial differences, being proactive and reaching out to people in a positive light may be just as rewarding and critical for advancement in facial differences awareness.

Future Implications for Study

In general, the research and findings of this study have proved to be constructive and useful. The aim of this project was not to prove, but to hopefully create more awareness and help build on the already existing knowledge about women with facial differences. Upon reflection, I believe that this study has several areas that may be modified, adapted, or added for future research on this population. This includes possibly recruiting participants of different gender, age, race/ethnicity, and nature of facial difference. It also means broadening future research to incorporate areas such as surgery and intimacy, while limiting other categories such as employment.

Participants

Future research in this area might possibly include male participants, as this study was limited to only women. It would be valuable to find out in more depth and detail about the experiences of men in relations to social functioning and methods of coping that may have developed. This current study also lacks the ability to compare and contrast between gender groups, so upcoming research may want to look into similarities and differences between and within male and female participants with facial differences.

The current study also does not include people under the age of 18 or over the age of 50. Even within this specific range of ages, there were no participants under the age of 25 so young adults were not accounted for in this study. Therefore, research modified to focus specifically on children, adolescents, or the elderly may be needed to gain a more comprehensive understanding of this population. Once again, gender may be a factor to consider, as there may be significant differences or similarities between or within genders

and certain age groups. Nonetheless, age would probably be an important characteristic to consider for future studies with people with facial differences.

In future studies, it may be critical to further examine more participants with acquired facial differences as their experiences may differ from participants with congenital facial differences. For this study, an unexpected and surprisingly large sample of participants had congenital facial differences rather than acquired. Consequently, the findings gathered from the interviews mainly reflected women who were born with congenital facial differences. However, studies with a focus on participants with acquired facial differences are needed because unlike congenital differences, participants have the added layer of experiencing some kind of change in their physical appearance. If trauma were also present, then that additional factor would be another possible major difference to look into between acquired versus congenital facial differences.

In particular, this study included a self-selected sample of women who voluntarily participated, making it reasonable to speculate that this group of women have adjusted and adapted quite well to their facial difference. The overwhelming prevalence of women with a cleft lip and palate compared to other facial differences may also suggest it is condition that people are best able to deal with. As one of the more common congenital facial conditions, it may not seem as permanent at the presenting level because of the surgical addressability and successful outcome in many cases. Still, future research involving a more random sample of participants is needed to better understand the experiences of women who may not feel as well adjusted or accepting of their facial difference.

For this project, the role of a participant's race and ethnicity was not studied as the overwhelming majority of women identified as White/Caucasian. Previous screening of participants did not include race/ethnicity, but all participants were asked during section I of the interview (Identifying Information) to state their racial identity for statistical purposes. In future studies, it would beneficial to study how one's race or cultural may impact their experiences of adaptation in relation to their facial difference. In addition, people of color who also have a facial difference would experience multiple levels of oppression, adding race as a separate dimension of adversity compared to Whites. Hence, studies in the future may want to explore racial significance for people with facial differences.

Finally, one major weakness of this study is the limited sample size of only 14 participants. Due to restricted time and financial resources, no more than 15 participants could be interviewed in depth for this qualitative study. Although this leaves a vast number of participants and their experiences unaccounted for, future studies could always benefit from increased sample size.

Surgery

During interviews, I was surprised by how frequent and in depth participants discussed reconstructive surgery and it's benefits towards healing and a happier sense of self. Even though earlier research had documented the use of surgery for functional and cosmetic reasons, I did not anticipate the salience of responses that directly related surgery with a person's level of acceptance, better school experience, and ways of coping. Although it was evident in the findings that participants did not believe surgery alone would resolve a great deal, it was shown that surgery did help participants achieve

a more positive sense of self and further acceptance from society. It may be possible to speculate that because participants noticed a friendlier reaction from other people after surgery, that kind of response may have helped contribute to a higher level of self-esteem and self-image. In return, this may have translated into a feeling of being more accepted into society and fitting in with other people who were not familiar with being around people with facial differences.

In future research, it may be of worth exploring in depth how reconstructive surgery may affect a person's level of self-acceptance and self-image. Although there have been numerous quantitative studies done on plastic surgery, it would be helpful to deepen that research by interviewing participants with some open-ended questions. Additionally, it might be important to also look into and compare the meaning and experiences of surgery for participants with congenial versus acquired facial differences.

Intimacy

The optional question of intimacy was included due to a general lack of knowledge and research about this issue in people with facial differences. I was particularly interested in hearing from women about their thoughts on relationships with any partners, and what they have learned about themselves in terms of intimacy. I was amazed because the vast majority of women were willing to contribute and share at least some aspect of their intimate lives, In fact, many women expressed positive feelings regarding intimacy and were comfortable exploring the issue in order to help strengthen this area of research that had previously not really been examined. As a result, I am more prone to believe now that the topic of intimacy may not be such an untouchable one in research. Further studies on intimacy may be useful, as the core idea behind intimacy for

many women seemed to be relationships and the level of connectedness they felt with others in the world.

Employment

One area of discussion that most participants did not find to be particularly important was employment. This contradicts previous research done by Stevenage & McKay (1999) regarding discrimination and it's undeniable presence at work. Stevenage & McKay (1999) mentioned biases in areas such as recruitment, hiring, and the general response or treatment from staff, employees, and employers. However, my research found that even participants with more rare facial differences did not necessarily feel they were treated differently at work. In general, most women could not think of anything significant that was related to their employment in relation to their facial difference, and did not believe they experienced any prejudice. So based on the feedback I received from participants, I would probably remove the question about employment if this study were repeated. Instead, a more direct question may be asked about any helpful strategies or techniques participants may want to share with other people who may feel they are at a disadvantage when it comes to employment matters. This section may be added to the positive learning/methods of coping question so that participants may have the opportunity to provide constructive advice for those who have experienced discrimination in the work force.

<div align="center">Summary of Discussion</div>

As a researcher, it has truly been a privilege to interview and work with the many women who have contributed to the research findings for this study. The objective of this project was to expand and enhance the general awareness and understanding of people

with facial differences, and perhaps provide support and hope for anyone who may be struggling to adjust to their own visible difference. In particular, the work focused on women, adaptation, and the advantageous coping methods or strategies that one had learned and wanted to share in their own words. Each participant's willingness to help and openness in response was truly encouraging. More qualitative and quantitative studies are needed in order to further deepen our understanding and awareness of this population.

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Appendix A

December 22, 2006

Fusang Carly Yin
10 Aldrich Street
Northampton, MA 01060

Dear Carly,

Your careful and complete revision has been reviewed and we are now happy to give final approval to your study. Thank you for sending copies of all the sections you deleted, as it made it much easier to follow your amendments. Again, let me say that the material you included was good material and some of it will probably be in your thesis, it was just not necessary to include it all in your HSR Application and particularly in the Consent. You have done a good job of cutting and clarifying your plans.

I did notice one typo in paragraph three, line six of your Consent. I believe you mean *in confidence.*

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain signed consent documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with this most interesting project. The emphasis on a strengths perspective will make it particularly useful for the participants and for others who might learn from them.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee

CC: Roger Miller, Research Advisor

Appendix B

Informed Consent Form

Dear Participant,

My name is Carly Yin and I am a second year graduate student at Smith College School for Social Work. I am interested in researching and learning about the positive and advantageous ways in which women between the ages of 18-50 with facial differences deal with the social difficulties they may encounter. In order to qualify for participation, you must either currently or sometime in the past have been working (full, part-time, etc.) or in school (full, part-time, taking classes, etc). Also, your facial difference may either be present at birth, or acquired due to some childhood or adult event.

One of the main goals is to listen to and explore from your perspective how you have best negotiated and handled the many social experiences that may have been related to your facial difference. I am really hoping to benefit from hearing about your successes, and the positive strategies you have found to be helpful or valuable in managing your personal and social life. The information collected from this study will be used for my master's thesis in social work and for possible presentation and publication.

As a participant, I will be asking you five main questions through a confidential interview session over the phone that is set up at your convenience. Once I have received this signed informed consent, I will contact you to make that appointment time for our phone interview session. The interview will take approximately no more than one hour depending on the length of responses and details given. The personal information I will need to know (during the beginning of each interview) but will hold in complete confidence through out the entire study will be your name, age, race/ethnicity, nature of facial difference, how long you have lived with a facial difference, and occupation. I will be using a digital voice recorder during our interview, and will also be taking notes during the course of this study. The purpose of the recorder and note taking

is to ensure that I have the most accurate and precise account of the information you are giving. I will also be doing any transcription on a needs basis (e.g. for clarification or analysis), and the transcripts will be disguised and kept confidential.

The risks involved are mainly emotional, and may include discomfort, embarrassment, distress, and feelings of pain and anxiety due to talking about unpleasant experiences. I understand that describing these highly sensitive and personal issues may be difficult and stressful. Therefore, you have the option of not disclosing any information you do not feel comfortable with, and may choose to withdraw from the interview at anytime if you wish to do so. Attached is a list of general referral sources that you may find helpful. I will also be glad to help you identify and look for some possible local resources if desired.

I believe that your participation in this study will be beneficial in several possible ways. I think there is a general lack of awareness about the stigma that individuals with facial differences encounter, and currently there is not enough research regarding women's personal experiences and how they impact oneself. Your contribution to this study will help add a unique and useful dimension to the topic of facial difference in women. It may also be possible that other women who may be experiencing similar feelings and emotions about their own facial differences may feel comforted and supported by your stories and experiences after reading them. During the course of this interview, your personal accounts of strengths and struggles may also offer you the opportunity to reflect about your experiences while educating others. Lastly, you will be entered to win a free 20-dollar gift certificate (a 1 in 15 chance of winning) to Borders Book Store for participating in my study.

Confidentiality will be taken very seriously due to the personal nature of this study. Once the interview session is over, your information will be under a unique code name assigned specially for you, and all information (recordings, notes) will be kept in a locked cabinet to help ensure confidentiality. My research advisor from Smith will be the only other individual who may

have access to the disguised information (no real names used, only codes). During publication and presentations, the information will be presented as a whole group and any identifying information will be carefully disguised or removed during any presentations of brief quotes or vignettes. As required by Federal regulations, all data collected will be kept in a locked cabinet for three years. After this time, all notes and transcripts will be shredded and the recordings will be erased.

Your participation in this study is greatly appreciated but completely voluntary. You may choose to withdraw at any time during or after the study has begun, and may choose to not answer certain questions in the interview. You will not be penalized for withdrawing, and all materials pertaining to you will be destroyed. However, you will still be provided with the list of referral sources and be eligible to enter the raffle drawing. The final date you may withdraw is on March 1st, 2007. Please feel free to contact me anytime with questions or concerns at fyin@email.smith.edu. Thank you for your time and effort.

Print Name_____

Signature_____Date_____

Researcher Signature_____ Date_____

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORUTNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Please keep ONE copy for you own records

Appendix C

Interview Guide

I.   Identifying Information

      A. Age:

      B. Race/ethnicity:

      C. Nature of facial difference:

      D. Years living with facial difference (if applicable):

      E. Occupation:

II.   Friendships/Social Experiences

      A. Ask-"I am interested in your relationships and social life, such as friends, family-do you mind briefly telling me a bit about your experiences around that?" Prompts if needed may include: "I was wondering if you could talk a bit about your family, and which people are significant in your life and why?"

      B. Ask-"What would be a social situation that you would feel most comfortable in and why?"

      C. Where in your life do you feel most challenging socially and how have you dealt with that?"

III.   Employment/School (as indicated by participant)

      A. Ask- "Could you briefly characterize what life was like at school or work?"

B. Prompts may include: "I was wondering how you felt about the (hiring or recruitment process) or (relationships with other school members), and could you talk a little bit about that experience?"

IV. <u>Positive Learning, and Methods of Coping</u>

A. Describe learning process and what participant finds helpful-"In this last question, I am interested in finding out if you have found any helpful or meaningful ways of dealing with any of these discomforting situations that you have share so far? How so?"

B. Prompts may include: "It may be really helpful for other people to hear about your stories because it gives them hope, strength, and possibly new ideas to help cope with their differences. Have you found any positive gains and strengths that you didn't recognize about yourself before that you might want to share?"

V. <u>Intimacy (Optional)</u>

A. Describe intimacy-"I am also interested in the area around intimacy, would you be willing to talk about that?" If so, "How would you describe your feelings about intimacy related issues?

B. Prompts may include: "Would you mind sharing your thoughts and feelings around a previous or current relationship?"

*The area in each section that says "prompts may include" are all ideas if there is allotted time or the participant is having difficulty answering the more open-ended questions.

Appendix D

Recruitment Form

Dear _____,

My name is Carly Yin and I am a second year graduate student at Smith College School for Social Work. I am interested in learning about the positive and advantageous ways in which women with facial differences deal with the social situations they may encounter. My aim is to listen and explore from your perspective how you have best negotiated and handled the many social experiences that may have been related to your facial difference.

The participants who may qualify for my thesis study include any women between the ages of 18-50 who have either been born with a facial difference or have lived with a facial difference because of some childhood or adult event. Also, you must either currently or in the past have been working (full, part-time, etc.) or in school (full, part-time, taking classes).

I am really hoping to benefit from hearing about your successes, and what you have found to be helpful or valuable in managing your personal and social life. I also hope to hear and learn about how you have best negotiated/dealt with the social experiences related to your facial difference.

The participation time will take no more than an hour (flexible), and will be a confidential phone interview set up at your convenience. All participants who volunteer to be in the study will be automatically entered to win a 20-dollar gift certificate to Borders Book Store. If possibly interested, please give Miss Debbie Oliver permission for me to call you soon to further explore your participation.

Sincerely,

Carly Yin (BA, MSW Intern)

617-816-0262
fyin@email.smith.edu