The Psychological Effect of Parents on their Children with Severe Facial Deformities and

Mental Disabilities:

The Challenges of Reconstruction for Severe Facial Deformity

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Table of Contents

Abstract

There was a social standard in society because of the stereotype of attractiveness. Individuals with severe facial deformities and mental disabilities were exposed to the struggles that involved the disadvantages of being the unattractive minority. The psychological stress that parents experience towards these conditions played a significant factor in their children's overall development. Genetic counseling and facial reconstruction were presented as valuable intervention strategies for the patients.

Chapter 1

Introduction

Background

The issue of *severe facial deformity* was widely impacted by the psychosocial significance of physical attractiveness. Beauty affected the cognitions of individuals as well as the quality of interaction patterns they experienced. Physical attractiveness was considered a valuable asset for an individual in society. It determined a lot about the individual's identity, attitude, and even a person's future.

Over hundreds of thousands of years, protohominids and human beings lived in groups of no more than 30. The biological capacity for the number of familiar or "safe" faces was quite small. These template faces and facial features, like all other neuro-developmentally determined templates for emotional, behavioral, and social functioning, were set during childhood (Field & Vega-Lahr, 1984).

In modern society, there existed a certain stereotype for physical attractiveness. They reflected how physical attractiveness was associated with social desirability, prestigious jobs, successful marriages, better parenting, and relationship management, and were more likely to find love earlier, compared to their lesser attractive counterpart (Elks, 1990). The stereotype for physical attractiveness could overall be constituted to a better life for those who were compared to those who were not.

The human eyes accept and believe to recognize only the norm and become comfortable with this norm. Among patients with oral-facial defects, psychosocial risk areas have been identified in this population. Characteristically, the research measures and studies one element of psychosocial function. Such research has revealed that patients with severe deformity may have significant psychosocial needs and problems in the areas of cognitive, emotional, behavioral, and family functioning (Efran, 1974).

Studies reflected that physical attractiveness influenced a number of social interactions and relationships for an individual's life such as heterosexual dating, peer acceptance, teacher behavior, employment interviews, even jury decisions (Elks, 1990). Attractive individuals received greater opportunities than unattractive ones. It was evident why parents would prefer to have attractive children. The most basic reason was because their children would live better and easier lives if they held some level of attractiveness.

It was also understandable how families with a disabled child experienced greater levels of parental stress according to the severity of their child's difficulties (Margalit, Raviv, & Ankonina, 1992). Disability was not associated with physical attractiveness. In fact, it could be the opposite because of the way disability could distort the familiar structure of the face and body of the individual. Disability could be directly related to the difficulties in achieving quality of life. Studies also reflected how parents with disabled children experienced difficulty in coping and stabilizing the family climate (Margalit et al., 1992). There was more tension in such households because there was a greater level of struggle to cope with the child's disability. According to Border and Strauss (1991), family instability was associated with birth defect. There were different factors that cause such instability such as guilt, sibling issues, and other social implications.

Research on the effects of attractiveness suggests that both adults and children expect unattractive children to demonstrate more behavior problems (Schneiderman & Harding, 1984; Tobiasen, 1987). It has been suggested that this assumption may be a self-fulfilling prophecy, resulting in children with facial anomalies to be at increased risk for psychopathology (Tobiasen, 1987). The parent-child interaction was a critical factor for their coping success.

This accounted for numerous psychological implications for both the adult parents and the children. While the parents struggle to become effective in dealing with their children's condition, the children experience the impact of their own disabilities with the psychological impact on parents of children having such conditions as well. Since parents should serve as a critical source of support for their children, intervention strategies should address the psychological needs of the parents. Intervention should be directed toward counseling the parents regarding both their condition and their children's condition through methods used in genetic and reproductive counseling. Facial reconstruction was also highly considered as an option for the patients with severe facial deformity. However, it was important to equally address the psychological needs of the patients as well.

Statement of the Problem

Attractiveness was associated with other factors for status generalization and stereotypes such as racial or sexual prejudice. It was a fact that physical attractiveness had occupied the role of society's gatekeeper to quality of life. It was perceived to be more difficult, though not impossible, for unattractive individuals to attain the things that attractive people have with lesser effort. Thus, attractiveness was beginning to be perceived as the foundation for a person's identity in the modern times. Studies reflected that attractive individuals had a significant advantage in society (Efran, 1974).

However, statistics showed that 1 in 40 babies were born with a major abnormality. Nevertheless, research presented little to educate and empower the parents of these children about their condition and options. Psychology practitioners needed to find a model by which they could service the needs of parents with these struggles.

Children with severe facial deformities and mental disabilities were easy victims in a society that used physical attractiveness as a measure for one's social worth. They needed a strong support system that would enable them to overcome these challenges. Children with

severe facial deformities and mental disabilities had different levels of attachments to their parents based on their capability to interact with their caregivers. The parents of children with severe facial deformity could not change the way society judged people. They could not control the world outside of their households. However, they could take control and manage their families. Since they served as the children's strongest support system, they needed to be equipped to deal with their children's condition and the condition of their future offspring.

This research would present methods of interventions through genetic and reproductive counseling in order to facilitate an effective interaction with their children concerning their deformities and mental disabilities. It would also provide the option of a facial deconstruction and other available sources of coping with this handicap.

Significance of the Study

The identification of the stressors that faced early human societies was observed to impact their survival reproductive success. It would be important to address the problems parents with children that suffered from severe facial deformity and mental disabilities in order to provide these families with a better quality of life. A rich array of literature was already presented regarding the psychosocial behavior as well as humanistic notions on attractiveness and beauty. These concepts were deeply imbued in the attitudes and perception of society towards individuals. It was became the basis for the world's perception on the inner being of a person.

This study would promote intervention strategies that would allow patients and their families to engage and grow familiar with what seems to be indifferent to the human eyes and have the proper tools to overcome the world's perception. It was important to guide the parents to become efficient support people for their children. It was understandable that even parents have their own struggles in adjusting their perception towards their children. Genetic

counseling would allow them to understand more about their children's condition and see beyond what the world sees and perceive the person beneath severe facial deformity.

The central finding of this paper would allow readers to understand the point of view of parents who found themselves with children with severe facial deformities and mental disabilities. It would present an understanding for the public, the psychology practitioners, and for other parents in the same situation about the issues that are related to these conditions.

Research Questions

The research would analyze the psychological effect of severe facial deformities and mental disabilities on the lives of children. The role of parents in the lives of children with severe facial deformities and mental disabilities would also be examined. The intervention strategies to address such conditions would also be presented. The research would answer the following significant questions:

1. How did severe facial deformities and mental disabilities affect the psychosocial functioning of the children?

2. What was the quality of the parent-child interaction in cases of severe facial deformity or mental disability?

3. What intervention strategies could be utilized in order to address the struggles of parents of children with severe facial deformities and mental disabilities?

Research Objectives

The research was designed to achieve the following research objectives:

1. To determine the impact of severe facial deformities and mental disabilities on the psychosocial functioning of the children and review the literature about the significance of physical attractiveness.

2. To assess the quality of the parent-child interaction in cases of severe facial deformity or mental disability and determine the problems involved in this relationship.

3. To present significant intervention strategies that could be used to address the issues of severe facial deformities and mental disabilities.

Scope, Limitations, and Assumptions

The research would deal with the impact of severe facial deformities on the psychological health of children. It would cover the discussion on the significance of physical attractiveness in society and parent-child interaction as major struggles encountered for children with severe facial deformities and mental disabilities. It would only include intervention strategies such as genetic and reproductive counseling as the major forms of counseling that would be analyzed for this paper. Facial reconstruction would only be briefly introduced with a focus on the importance psychological preparation for this procedure. The discussion would widely revolve around and be limited to engaging and empowering the parents to be efficient support systems for their children.

The general assumption of the paper would be the reader understood what mental disabilities were. They would not be further classified and expounded according to their forms or causes the way facial deformities would be.

Summary

This chapter introduced the issue of severe facial deformity and mental disabilities in children. It discussed the psychosocial significance of attractiveness for individuals in society. It presented the research gap that addressed the needs of parents who had difficulties understanding, coping, and addressing the struggles of having children with these conditions. There was limited research regarding intervention strategies for children with severe facial deformities and mental disabilities. The chapter also presented the significance of the study in terms of providing families with disabled children a better quality of life through effective intervention strategies. The research questions and objectives that would provide direction and guidance for this study were also presented as well as the scope and limitations that

would be followed. The next chapter would include a review of related literature that would

present a rich discussion on the psychosocial effects of severe facial deformity and mental

disabilities on children as well as the perceptions towards such conditions.

Chapter 2

Review of Related Literature

Introduction

This chapter would discuss the significance of person's face in relation to the challenges of individuals with severe facial deformities. The discussion would continue in analyzing the issues that individuals with facial deformities encounter based on the presented notions and stereotypes of physical attractiveness. It would also extend to address the separate struggles that children with mental disabilities encountered. Intervention strategies that had worked from past studies would also be presented and analyzed. It would also focus on the parent's attitudes and reactions towards having children with mental disabilities.

The Significance of the Face and Facial Deformities

More than any other body part, the face served as the site for the beauty and attractiveness of a person. It also served as the person's identity because it was the only body part that truly distinguished one human being from another (Elks, 1990). It would not be wise to downplay the significance of a person's face in a human's life. It was something that influenced human interactions and social judgments, specifically for first impressions.

In relation to this, facial deformity was related to unattractiveness since it evidently did not meet the standards for facial beauty or attractiveness. Facial deformity was defined as "the strength of negative reaction by the possessor, and others, to a particular facial feature, or set of features. Without this negative reaction, "a facial deviation is simply a difference and not a deformity" (Elks, 1990 p. 36). Facial deformity could be classified through the degree of negative reaction it produced.

The first level of deformity involved a slight or a mild deviation (Elks, 1990). It was not apt to attract much attention from those looking at the person's face. Deformity needed to be pointed out in order to be notices. However, individuals who possess such deformity could

still develop distress over it. The second level of deformity involved a moderate form. It was

something that was noticeable and could elicit teasing, curiosity, or staring. Nevertheless, it

did not merit any violent reaction. The third level of deformity involved a marked face. This

was something that was more noticeable. It was also more likely to produce strong reactions

from others. It was also something that could elicit repulsion, jokes, pity, deliberate

avoidance, and prolonged staring (Elks, 1990). The highest level of deformity involved gross

levels of negative reaction. It was described as deformity that was shocking and repellant to

others. It was also something that evoked violent reactions, repulsion, pity, and even horror

from the face's viewers (Elks, 1990).

The significance of the face was based on its centrality and prominence in human

interactions. It constituted one's judgment for physical attractiveness. A person with facial

disfigurements was bound to experience negativity because of the stereotype of

attractiveness. It was also related to negative experiences in employability, marriageability,

and sociability, among other things (Elks, 1990).

Studies reflected different effects of facial deformity. Most of the time, individuals

with facial deformity were reluctant to go out in public because of experiencing stares and

rude remarks (Elks, 1990). They usually felt like they were objects of curiosity or pity from

strangers. They also expressed difficulties in making friends, getting married, and obtaining

good jobs because of the disgust in the expressions others have towards them. They also

experienced people standing significantly further away from them and closer to non-

disfigured individuals (Elks, 1990). There existed a social stigma against people with facial

deformities.

Individuals with these conditions were regarded to be social inferiors and hold a

minority status, similar to other marginalized groups. Despite the fact that they were capable

to do the same work as their non-disfigured counterparts, they were still denied of such work

opportunities. Social participation was altered or affected in one way or another by facial deformity.

Causes and Forms of Facial Deformity

There were three major cause of facial deformity; namely, congenital, acquired, and products of treatment from deformations (Elks, 1990). Congenital causes of facial disfigurement are due to malformations, starting from prenatal life. Examples of congenital facial deformities included facial atrophy, excessive facial height, cleft lip or palate, bucktooth deformity, Crouzon's disease (frog face), and colombomata of the lower eyelids (Elks, 1990). When facial deformities were acquired, it meant that they were caused by different sources of trauma within a person's life. Automobile accidents, fires, athletic injuries, frostbite, and wars were examples of causes of such deformities. The last form of facial deformity was caused by treatment sequelae. These were for treatment of other disfigurements such as surgical loss of a portion of a face, scarring, and skin graft distortions (Elks, 1990).

The prevailing misconceptions and perceptions of society towards facial deformities further increased the burden of individuals with these conditions. Since there was a social premium on physical attractiveness, the attractive face was perceived as a symbol of success and it was even considered as a saleable commodity (Elks, 1990). Even the simple occurrence of face aging constituted to a negative value because of its consequences to the face as well as its owner. There was also the existing prejudice against facial features that were brought about by ethnic origins such as a prejudice for Negroes and Jews that demanded for alterations for certain distinguishing facial features (Elks, 1990). Furthermore, there were also beliefs in folklore and superstition that relates deformity or disfigurement to ancestral sins or punishment for wrongdoings (Elks, 1990). This condition was then associated to the cursed child.

Issues for Individuals with Facial Deformities

There were significant issues that individuals with facial deformities had to face as a result of their condition and as an effect of the world's perception towards facial deformities. These issues needed to be discussed in relation to what parents with children having this condition should be aware of and develop an understanding for.

Psychosocial Status.

Literature presented that individuals with facial defects experienced psychosocial risks based on studies of self-concept, psycho-educational development, social perception by peers, and the public (Broader & Strauss, 1991). These could be significantly correlated to the established stereotype for physical attractiveness.

Broader and Strauss (1991) conducted a study on adolescents with cleft lip and palate. The results of their study showed that appearance and speech were problematic areas in their psychosocial development despite having extensive surgery and care. This study also reflected the connection between speech difficulties and facial deformities as well as the report of a higher rate of behavioral and learning problems at home and in school. The population of students with cleft lips and palates were described to have lower verbal IQ scores and language deficiencies (Broader & Strauss, 1991). They were also observed to underachieve despite their intellectual capabilities.

Children were also at risk of developing low levels of self-concept. Thus, this poor self-conception was also related to the development of behavioral problems, inhibition, and shyness (Broader & Strauss, 1991). Furthermore, adjustment and achievement problems were also recorded with lesser incidents of dating experiences and later marriages.

Broader & Strauss (1991) presented in their findings that more than half of the patients in the Oral-Facial Program had problems that needed psychosocial referrals. These referrals were described as cognitive delays, behavioral deficits, and family and/or emotional

instability. They presented that individuals with oral-facial defects were placed at a higher risk for psychological dysfunction.

Internal and External Manifestation of Disability.

Weis (1994) analyzed the struggles of children with internal and external defects and initially discovered that most children that suffered from external defects or physical deformities were placed at a higher risk of being abandoned, even if they did not suffer from any life-threatening illness. This meant that their disability only revolved in the aesthetic feature of their body. The misconception was that physical deformity was a symptom for disease and, if the deformity did not exist, the disease or the disability did not exist. While this was true in some cases, it was not also a fact (Weis, 1994).

Children were usually rejected because of their gruesome appearance due to deformity. Nevertheless, it did not mean their bodies were not normal or were not capable of normal development. There were numerous cases wherein normal children that were born with a cleft lip or lacking in a portion of their facial features were abandoned by their parents in the hospital due to their facial deformities. Parents rejected their children, not on the basis of the severity of their disability, but on the level of facial deformity. In the same manner, aesthetic improvement of their appearances attributed to the acceptance of the parents despite the severity of their diseases (Weis, 1994).

Beuf (1990) noted how parents were observably less responsive towards their newborn infants due to their impaired appearances. They were observed to bond less with them and touch them less often. The development of the infant's self-esteem could be impaired since this was a critical stage in the development of a person. Each stage of a child's development constituted to different levels of risk of poor self-conception depending upon the environment that nurtured them.

Misconceptions from Facial Deformity.

There were numerous works that identified important misconceptions when it came to facial deformity and the way the public perceived these individuals (Frances, 2004). The first misconception was regarding the bravery of the person. This was associated the battle scars or marks of bravery that were often generalized to all individuals with facial deformity. These individuals had little choices concerning their physical appearances. They would be susceptible to fear and depression in dealing with the way they looked.

There was also the misconception that these individuals would be alright after surgery. It seemed as if people thought that there were easy cures for such deformities and ignored the fact that the level of severity had nothing to do the with distress people experienced towards them (Frances, 2004). It did not matter if the deformity was severe or mild. This misconception risked these individuals to disappointment and further depression occurred if expectations of the surgeries were unmet. While surgery was an effective treatment to many facial deformities, it was not also applicable to all disfigurement cases.

There was also the myth regarding the horror people held for people with facial deformity. People were usually afraid of what they knew nothing about and what was different due to the need of individuals to confirm to society's stereotypes. The media always portrayed disfigured people as evil and, as a result, people end up fearing them or ridiculing them (Frances, 2004). The truth was that morality was not a matter of physical appearance; it was about the person's character. The deformed face of a person did not symbolized distorted values and morality.

People also expected individuals with deformed faces to have second-rate lives (Frances, 2004). They already presume that these individuals have no future because of the evident odds against them in a stereotypically driven society. In reality, if these people were

empowered by a support system and aided with the right attitude, they could be capable of living full lives.

Parental Acceptance.

The children that were perceived to be normal or had the average level of attractiveness had the tendency to receive more levels of affection than those children with disabilities (Weis, 1994). Beautiful was good and a beautiful child was expected to be good and have positive personality traits as well as high scholastic achievement rates even as young children. Parents tend to be bonded more and paid closer attention to children that were attractive. To illustrate, adults take more time documenting the milestone moments of their children's life through photographs or experience more pleasure looking at photographs of attractive children. Aside from the initial response on the identification of the infant's sex, the first level of contact involved the examination of the external appearance of the child. Mothers usually checked their babies' bodies carefully from birth (Weis, 1994).

Struggles of Children with Disability

The discussion of this paper would move beyond facial deformity. It also included the children with mental disabilities along with the said condition. It was important to recognize the separate struggles that children and their families encounter as a result of disability.

Issues with Handicap Identification.

There were also issues that were associated with mental disability identification. Unlike facial deformity, it was not easily recognized. It needed to be identified through different factors in order to be diagnosed and treated. The severity of the condition served as an important factor for recognizing the disability. It was important to identify earlier on if the children had mental disabilities. Identification usually depended on the familiarity of the observer and awareness of the factors that enabled individuals to recognize handicaps in the children's performance.

The first factor that constituted to identification was the severity of the condition. This referred to the extent by which the characteristics of the child interfered with adaptation to normal, everyday life (Berkson, 1993). Different cases reflected different levels of severity and even more than one disability. The second factor involved cultural and situational factors. The social environment played an important influence. Social stereotypes were a part of everyday life. When people failed to experience the same things, they were often associated with negative perceptions. Most of the time, negative stereotypes due to such instances were harmful to children (Berkson, 1993).

Children Perception of Disabilities.

The stereotypes towards unattractiveness and disabilities were usually observed with adults. However, even children held certain perceptions towards disability. Longoria and Marini (2006) noticed that younger children had less realistic views of children with disabilities than their older counterparts. When they grew older, the children's awareness of these disabilities grew. They developed capabilities to assess the strengths and weaknesses of children with disabilities. There were also reports that revealed how children that were as young as three years old did not choose to discriminate against the presence of disability when choosing a playmate. However, as they grow even a year older, their preferences for playmate selection began to involve physical appearances as a factor (Longoria & Marini, 2006). In fact, children that were as young as four years old were already able to classify mental from physical disabilities. Children also held negative attitudes towards children with disabilities even in areas that were not related to the impairment. There were some differences in attitudes in male and female children. Girls were more capable of exhibiting positive attitude towards disability while boys viewed individuals with disability to require more assistance and to be unhappier.

Communication Difficulties.

Children with disabilities were perceived to have a limited ability to communicate on a sufficient level (Trief, 2007). Communication could be described as the process by which individuals exchange information about their desires, needs, knowledge, and so on. It was described as the tool that developed social closeness, bridged information sharing, and fulfillment of social etiquette responsibilities. Young children usually communicated through gestures and basic vocalization before they learned to speak. However, it was possible that children with mental disabilities could learn to compensate through augmentative and alternative communication because of their limited verbal communication. These modes of communication included unaided modes of communication such as gestures, facial expressions, and signs (Trief, 2007). It was important for these children to be in constant communication with competent communicators such as their teachers, parents, caregivers, and therapists. Competence meant they were allowed opportunities to communicate through taking turns, making choices, and interacting socially in order to facilitate optimal communication with children with disabilities.

Intervention Strategies for Children with Disabilities

Research explored numerous intervention strategies. These strategies presented different factors by which researchers believed a child with disability would be able to be empowered to cope and live full lives despite their condition.

Team Support System.

Berkson (1993) encouraged a team to plan for the child's treatment. It required teamwork from the family and at least one professional in order to create a plan that was unique to the individual for a specific time frame. It needed to include the child's current abilities and skills. It determined a treatment or education plan by which medical, psychological, and educational services would be based. Parents needed to be intimately

involved in the process of decision-making for the education and treatment of their child

(Berkson, 1993). This was not only because they had the right to do so but also because they

knew the child better than any other person and recognized that the success of the procedures

would widely depend on their level of understanding and support.

     A number of cases involved children with more than one handicaps or were

handicapped in multiple aspects. This meant that more than one professional person needed

to be involved in the team (Berkson, 1993). Most of the time, the team involved a

psychologist, a social worker, a teacher, a physician, and a member of the family. When

speech impairment is observed, a speech therapist was made a member of the team. The

professionals' competence was important for the success of the child's program; however,

nothing could be accomplished if the parents were uncooperative in helping their child

throughout the treatment plan.

Integration.

Research also used the intervention strategy of integration when it came to

educational plans. Vaughn and his colleagues (2003) described young children with

disabilities to improve social functioning as a result of integrating them to general education

classes. Social functioning was improved due to exposure to a different range of social skills

interventions. Social skills interventions were observed to produce positive social outcomes

from integration class settings because educators did not need to implement any specific type

of social skills intervention but provide a whole range of socialization for the children

(Vaughn et al., 2003).

The play activities that were related to this intervention were an important feature.

Children in the developmental stages that were exposed to playing with normal kids held this

as an important aspect in their life. It enhanced their ability to interact and increased their

confidence to socialize with other people. It was often encouraged for educators to structure

their play activities in such a way that they promoted the appropriate skills for child-to-child interaction. They could also structure their play activities in such a way that they provided interventions for behavioral contingencies for appropriate and inappropriate behaviors of children with disabilities.

Profile Creation.

There was also the strategy that was used to address children with disabilities that involved profiling. A personal profile was a concise summary that described the child in a holistic manner. The information found in this profile involved the strengths, likes, dislikes, family composition and characteristics, as well as the circumstances for the most productive learning experience (Kelly, Siegel, & Allinder, 2001). The profile would serve as a collection of information that was gathered from the influential adult in the child's life. It could be obtained through interviews with professionals and family members as well as a review of the existing written records concerning the child. This document provided a quick view into the child's current interests as well as his or hers level of performance and development. This profile provided a more comprehensive perspective about the child. It would de-emphasized on the focus on the deficits of the child due to the disabilities and focus on the positive attributes and what the person had to offer (Kelly et al., 2001).

Parent Support Groups.

Solomon, Pistrang, and Barker (2001) discovered that the parents of children with disabilities found it helpful to belong in support groups. They found it satisfying to belong to such groups wherein they experienced high cohesion, expressiveness, task orientation, and self-discovery. This finding was based on the grounded theory analysis of a focus group discussion. Support was helpful on a sociopolitical level because it involved the development of a sense of control and agency for the parent within the outside world (Solomon et al., 2001). The interpersonal benefit of this strategy involved a sense of belongingness to a

community (Solomon et al., 2001). It also offered that intraindividual benefit that promoted

self-change (Solomon et al., 2001). There was an overall theme of identity formation for the

parents from the support group basing on the three benefits mentioned.

Families with Disabled Children

       Family Characteristics.

       There were significant differences between families with children that had mental

disabilities and those that had none. Children with mental disabilities were seen to violate the

norms to appropriate family roles (Bornstein, 1995). Different implications were associated

to the lack of portrayal of such roles that should have belonged to the child with mental

disability. Non-disabled siblings take on different roles that would normally be observed

(Bornstein, 1995). Role tensions were observed to be experienced by non-disabled siblings.

Most of these were probably due to increased responsibility to take care of the disabled child

and the prevention from enjoying the maximum benefits of childhood due to their disabled

sibling's condition.

       It was observed that families with such children were prevented from moving in a

normal family life cycle. Since families also develop as they undergo the dynamics of family

life from the early years of marriage towards the letting go of the children and the

development of the new family cycle, parents were seen to be stuck in the issues of parenting

their disabled children (Bornstein, 1995). Despite this, it was observed that families that were

more affluent coped better in the same way that mothers in better marriages adjusted better

than those in single parent households.

       The Significance of Child to Parents.

      According to Bornstein (1995), as human beings, individuals played the role of

meaning-makers. Humans had the tendency to derive meaningful understanding from certain

events in their lives. This reflected the question as to what a child with mental disability

meant to his or her parents. The focus on meaning was observed through interactions between the children with these disabilities and their parents.

Families have a complex meaning systems for the family and its individual members. There were different social constructions that were held by families of the children with mental disabilities. These families felt that this condition required intensive intervention. The day-to-day lifestyles of such families change in order to accommodate what they valued the most.

The social construction of disability was observed to start but not end in the home. However, the homes of these children with disabilities were an important place to understand in terms of social constructs. Territorial behavior and social construction were analyzed in terms of socially constructing the understanding for disability. Animals usually marked their territory the same way people marked their boundaries. Humans also have territorial behavior that reflects in different forms. The boundaries that humans placed around themselves were seen as actual lines that would translate into a physical separation or invisible imaginary lines that separated them from other humans. When it came to children with disabilities, territorial isolation was something they commonly experienced. In a family, they were usually assigned a certain place in a home or a role in the family that, in a way, territorially isolated them because of their condition (Weis, 1994).

They usually felt the stigma of their disability despite the fact that the family members did not want to have these stereotypes to be experienced by the child with disability. It was something that could be unconsciously constructed due to the social perception and understanding of mental disabilities. This behavior of parents reflected that a child was defined as their own if they were normal and did not pose a threat to their social status (Weis, 1994). If they treated their child in a manner that was less than how they would treat a normal

child, there was some kind of justification because their actions were directed towards a

foreign entity (Weis, 1994).

Mother's Reaction.

There were different factors that affected the mother-child interaction. The first one

involved the chronological age of the child. Mothers were observed to have emotional

reactions and concerns for children with disabilities. After waves of depression over the

child's first year of life, parents would go in and out of sadness until they accepted their

child's condition as the child grew older (Bornstein, 1995). There were high levels of

maternal concern observed for the milestone years of the child's life in terms of walking,

talking, toilet-training, and so on. The periods wherein mothers get emotional over their

child's condition involved birth and periods wherein milestones should have occurred.

The nature of the disability also affected the mother-child interaction. Mothers of

autistic children were more upset and disappointed in comparison to mothers of children with

Down syndrome (Bornstein, 1995). In the same manner, mothers of children with cerebral

palsy were less concerned with milestones than mothers with children with Down syndrome.

The characteristic of the disability influenced the emotional reactions of the mothers.

The personal characteristics of the mothers also played a crucial role in the

interaction. Mothers that were more shy, anxious, and withdrawn reacted differently from

stronger-willed women (Bornstein, 1995). On the other hand, mother's interaction with their

children was also affected by the reactions of the fathers. Fathers were more likely to be

concerned with the cost of caring for the child and what the child would mean to the family

as a whole (Bornstein, 1995). The presence of strong support networks was essential for the

mothers to cope with their children's mental conditions.

Parent-Child Relationships

It was understandable for parents to anticipate the birth of a healthy child. Even before the child was born, the parents were probably envisioning the child's future achievements in school, success in their careers and marriages, as well as the birth of their grandchildren. The birth of a handicapped child could mean the devastation of the dreams they have for their children (Horne, 1985). Parents needed to undergo different stages of recognition in order to achieve acceptance of their child's condition and to reassess their expectations for their children.

Withdrawal or Rejection.

Ziolko (1991) noted that abnormality was one of the parents' greatest fears during pregnancies. The realization of such fears would leave the parents with the task of caring for the child while they grieved for the loss of their expectations. Parents who could not bring themselves to accept this fact withdraw from the situation and form the child on a physical or emotional basis. Parents could find themselves unwilling and unable to visit the child's nursery or be emotionally uninvolved in the child's case. The child's disability could produce inhibitions for the parent's stimulation and subsequent attachment.

Denial.

Parents were usually caught off guard to see or to hear diagnosis of the handicapped condition of their child. To most of them, they would not be able to accept such diagnosis and tend to take on a form of denial as they search for a physician that would contradict the disability diagnosis (Ziolko, 1991). When the child did not have any outward signs of disability, the parents would be more unwilling to accept such diagnosis. When the child had a highly visible defect, parents tend to withdraw from social interaction to avoid public shame and discomfort (Ziolko, 1991).

Fear and Frustration.

The grieving process could reflect worse than the initial shock and when the denial dissipated. Parents tend to feel that they were losing control because of the depression and other conditions they develop as normal aspects of grief (Ziolko, 1991). This was a period wherein they needed to express their feelings through voicing it out, crying, exercising, or any type of creative work. Since people grieved at different rates, the parent's spouses could or could not support each other during such times. The grief was dominantly due to their feelings of guilt and responsibility for the child's disability. The lack of sufficient information was the reason for such anxiety (Ziolko, 1991). If they were unable to receive this information or release the grief inside, they tend to develop a neurotic approach to parenting their child (Ferguson, 2002). From neglect to overprotectiveness, the approach they would take would be perceived as extreme.

Adjustment.

Parents could only constructively cope with the disability of their children after they have acknowledged the irreversibility of the condition and understand its implications (Ziolko, 1991). The acceptance of the disability involved a certain level of tolerance for the child's limitations and an appreciation of the child's positive uniqueness. Parents in this kind of relationship with their children involved carrying out programs that would benefit their children. Well-adjusted parents were able to understand the reality of their child's limitations and support them in whatever way possible, especially on an emotional level.

Summary

This chapter provided an extensive review regarding the psychological effects that facial deformity and mental disabilities have on the parents of the children that had them. It involved the social construction of what it meant to have deformed face and mental

disabilities. The next chapter would include the intervention strategies that would address

specifically the parents of the children with severe facial deformity and mental disabilities.

Chapter 3

Methodology

Introduction

This chapter would involve a discussion on the methods by which intervention strategies could be implemented in order to address the needs of the parents with children that had severe facial deformity and mental disabilities. It would discuss the target population for this study. Intervention strategies such as genetic and reproductive counseling as well as facial reconstruction would be described and presented as valuable approaches.

Target Population

The focus of this study involved the parents of children with severe facial deformity and mental disability. It was important for parents to address the issues they faced when it came to the condition of their children. This group was selected for the potential of reconstruction for children with severe facial deformity. While insurance companies deemed these operations to be for cosmetic purposes alone, craniofacial plastic surgery could correct the abnormalities of the face, skull, and neck. This could provide the children with the significant psychological, social, and emotional benefits that can help them attain a better quality of life. Furthermore, this project will provide substantial information that would contribute to a counseling psychological method that will help both children with severe facial deformity and mental disability as well as their families and support groups.

Approaches to Intervention

There were different stages that were applied to counseling families of children with disabilities. Progression through the different stages should be done in a flexible and fluid process and must be focused on the child's overall development. The structure of each counseling approach must be goal-oriented and, at the same time, flexible for individual differences (Ziolko, 1991).

Description of Genetic and Reproductive Counseling.

Research on the effects of attractiveness suggests that both adults and children expect unattractive children to demonstrate more behavior problems (Schneiderman & Harding, 1984; Tobiasen, 1987). It has been suggested that this assumption may be a self-fulfilling prophecy, resulting in children with facial anomalies to be at increased risk for psychopathology (Tobiasen, 1987). Different forms of counseling could be employed to prevent parents from sending out negative expectations after their discovery of their children's conditions. In the case of children with severe facial deformity, genetic and reproductive counseling was one of the approaches that could be considered. Reproductive counseling involved prenatal services wherein couples were able to understand the genetic indications of their pregnancies. It would help them make decisions if they needed to continue or terminate a pregnancy or to practice other forms of methods in the form of contraceptive procedures or prenatal treatments.

The focus of this approach involved genetic counseling. Genetic counseling could be done at different stages in a person's life. The most common kind occurred during the prenatal stage. Prenatal genetic counseling involved women who were either pregnant or considering having children. The reasons they seek counseling involved a history of infertility, miscarriages, still births, exposure to medication, drugs, chemicals, their ages, abnormal ultrasound findings, previous child with birth defects, and so on (National Society of Genetic Counselors, 2009).

In this case, pediatric genetic counseling was the approach that would be presented as a viable source of psychological empowerment for parents who were considering facial reconstruction for their children. Pediatric counselors were usually involved with newborns, children, and their families. Parents go to pediatric genetic counselors because their children had birth defects or multiple congenital anomalies, mental disabilities, sensory impairments,

metabolic disorders, or suspected genetic disorders (National Society of Genetic Counselors, 2009).

These counselors help the parents understand the causes and implications of such conditions. They were also placed at a position wherein they could empower the parents to make decisions by providing them sufficient information regarding their options. They could explain to the parents exactly what the conditions of their children where in terms wherein they could understand and develop an informed awareness or not. This meant that the patients needed to make decisions for themselves based on objective information given to them.

There were different forms of counseling sessions. Some genetic counseling sessions involved one visit only. Other times, multiple sessions were needed in order to collect additional information or to update families regarding the ongoing medical dilemmas (Resta, n.d.).

Components of Genetic Counseling.

The first step of genetic counseling involved the gathering of information. This served as an important part of genetic evaluation. The family history, usually recorded in the form of a pedigree, provided clarity for the relationships and phenotypic features that could be related to the diagnosis (Baker & Schuette, 1998). Medical history was also obtained. The initial understanding of the client regarding the reason for referral and expectations throughout the sessions are then relayed. The verification of the diagnosis was the next step. It involved more than the genetic diagnosis that was given in medical records. The confirmation of suspected diagnosis of diseases required different evaluation sessions.

Risk assessment involved the implications of the genetic diagnosis. It centered on the client's concerns on the future health risks of the patient (Baker & Schuette, 1998). When a condition involved multifactor, risk assessments in family counseling involved observations from the family members of affected individuals (Baker & Schuette, 1998). The next step to

the diagnosis or risk assessment included the process of information giving. In this stage, the genetic counselor would describe the condition, the variability, and natural history in order to make sure the family viewed the disorder in the appropriate light (Baker & Schuette, 1998). Medical, surgical, social, and educational interventions that could address the problems would be described in relation to the available resources of the families.

Psychotherapeutic Model.

Genetic conditions could appear without warning. Genetic counselors were significant when families discover the birth of an abnormal baby. The counselors worked not only for the families to understand the cause for the problem but because they could help the families grieve the loss of their expectations for a normal child (Baker & Schuette, 1998). The counselor could provide information and ongoing support that could continue through subsequent pregnancies, at a time wherein families and friends could be uncomfortable to discuss about the baby's defect.

Families could not effectively process the information they get from genetic counseling when they have not learned to deal with the powerful reactions that these pieces of information could provoke (Baker & Schuette, 1998). A skilled genetic counselor could recognize and elicit different factors that were described as normal responses and reassure clients that their reactions were normal.

Psychological Aspect of Facial Reconstruction.

Facial reconstruction was a valuable option for children with severe facial deformity. It was something that could alter the way the world sees them. While physical attractiveness should not define a person, reality revealed that the advantage was still on the court of those who were attractive. If this advantage was sought to be obtained, facial reconstruction was an option for some cases. Psychological preparation was vital in order to have a successful outcome from such a procedure. People who coped least with facial deformity were also

perceive to cope least after facial transplantation and the long-term impact it would have on their lifestyles (NHS, 2008). Psychological beliefs and behaviors were perceived to influence the good outcome of such procedures. Aside from this, medical qualifications also needed to be satisfied because there were some cases wherein facial reconstruction would do worse rather than help the individual. It was important for the person to be psychologically secure in one's self, with or without facial deformities, in order to cope and attain the desired quality of life.

Summary

Genetic counseling could be considered as an integral component of a program that provides guidance to the parents in understanding what their child's condition was about. An individualized family counseling method should be designed for parents of children and families who were still adjusting to the birth of a child with a facial deformity. Reproductive counseling could be given to educate parents regarding the likelihood of future children that could be affected by the same conditions. Genetic testing can be initiated and the geneticist could discuss the prognosis of the affected child. Performing a social and psychological assessment provides support and resources to the parents and may prevent future problems.

Chapter 4

Results

Summary of Findings

The research focused on a psychological discussion about the parents that had children with severe facial deformity and mental disabilities. The study addressed the research gap concerning the necessity for intervention strategies that would address the struggles of parents to understand, accept, cope, and address the struggles that were related to having children with these conditions. The research aimed to understand the perspective of the parents regarding this experience and the intervention strategies that were presented that address disability.

Society was driven by the stereotype of attractiveness. The face held such significance because of the role it played in social interactions. Attractiveness was perceived as an advantage for people. It was something that was associated with high the quality of lives. The face was one of the reflections of a person's attractiveness. In this regard, facial deformities constituted to the opposite. It represented negative implications for the life of a person and the hindrance for receiving full lives.

There were different issues that were related to facial deformities. The most evident issue involved the psychosocial effect of people with facial deformity. Furthermore, studies also showed that parents preferred children with internal disability rather than those with external disability. This spoke highly of the greater struggles parents had with accepting children with both internal and external manifestations of disability and deformity. There were also significant misconceptions regarding facial deformity. These were dangerous because they negatively create presumptions regarding individuals with facial deformity.

Children also struggled with disability. It was important to identify the handicap earlier on in order to be addressed. It was also perceived that non-disabled children grow into the knowledge of what disability was and that negative perceptions increase through age.

Disabled children were also observed to have poor communication skills due to the barriers they encounter, especially in mental disabilities.

Intervention strategies were discussed. These strategies were important to be analyzed in relation to the intervention approaches that were presented in the third chapter. Support groups were perceived to be vital in the parents' process of acceptance and empowerment. It was observed that the relationship between the parents and the disabled children were affected because of the disability. The signs of these impact included rejection, denial, fear and frustration and then, for positive outcomes, adjustment.

Genetic and reproductive counseling was an important approach to be provided for parents of children with severe facial deformity and mental disabilities. It could be through such sessions, modeled to provide a psychotherapeutic approach, that parents would be aware of their children's conditions and act upon creating action plans to help them achieve the quality of life they deserved. Finally, it was important to remember that facial reconstruction, by itself, would not solve the problem of children with severe facial deformities. It was still a challenge to the psychological aspects of the individual because of the psychosocial stress it would have on a long-term basis.

Results and Discussion

Severe facial deformities and mental disabilities widely affected the psychosocial functioning of individuals. Research showed that society had high regard for normalcy according to a person's attractiveness. There was a stereotype against individuals with disabilities and deformities on a separate level. However, when these two conditions were perceived in one person, the level of challenges was bound to increase.

Society placed a certain label on individuals that were considered abnormal. Members of society were observed to repel from people who did not meet the standards of attractiveness that was considered acceptable. Facial deformities elicited second-looks,

teasing, avoidance from people, pity, and even disgust and horror. This was despite the fact that these individuals were still humans in spite of their external appearances.

The social construction of disability explained why individuals with disabilities or deformities were considered as social outcasts. It showed that, as territorial beings, humans tend to isolate themselves from beings that were not similar to them or did not qualify to the norms of what was socially accepted. This provided for poor opportunities for social interaction. The lack of chances to interact on a healthy level with other people created poor self-concepts in terms of shame and self-loathe because of the way they looked and acted.

Parents experienced the struggles of their children's deformity and disability. It was, because as infants, they would not really understand the consequences of their condition. The parents were the first to experience the extreme distress that was related to the loss of their dreams and expectations for their children. It was also the parents who feel fear and frustration for the future their offspring would endure due to such conditions. Parents tend to exhibit different reactions from this experience. There would be cases that they would reject or deny the child. However, in most cases, parents would be able to adapt and accept with their children's conditions. It was possible for the relationships they have with their disabled children to be different in comparison to how they would treat and perceive their non-disabled children. Most of these negative reactions were rooted out of the lack of support and information they needed to address these conditions.

The development of intervention strategies for a child with a disability required the assessment of the child's unique conditions and the selection of the most appropriate strategies. However, it was important to recognize the needs of the parents as well, if not prioritize it earlier on. The parents greatly affect the development of the child and the more they stress over the child's development, the more the effectiveness of the treatment programs could suffer (Lessenberry & Rehfeldt, 2004). It was important to deal with the

parents' struggles and attitudes towards disability in order to effectively address the needs of the disabled child. The parental stress was seen to affect the psychological health of the children with disability as, when the parental stress increases, the quality of interactions and support they had for their child decreases as well (Lessenberry & Rehfeldt, 2004).

Genetic counseling and facial reconstruction were different approaches to interventions in these cases. As mentioned, the intervention approach would all depend on the individual need of the child. It would differ in one way or another for different children. The important consideration was the fact that the children's parents were made aware of the condition of the child in the best possible manner possible. Genetic counseling could provide a valuable source of education and support for these parents.

Implications

It was meaningful to produce an intervention strategy that fit like a glove to the condition and personality of the child. More than disability and deformity, it was important to consider who the persons involved were. The personality of the parents and the disabled children were an important consideration in the process. Kelly and his colleagues (2001) presented the personal profile for children with disabilities. This was something that could be utilized in counseling sessions, including genetic counseling. Since the profile focused on the assets and personality traits of the child and the family, more than the medical records, it would serve as the snapshot for clients of genetic counseling.

Recommendation for Future Study

It was important to further investigate on the intervention strategies that would involve parents of the patients that did not qualify for facial reconstruction. This was not covered by this research but would highly benefit a part of the population of the disabled that were denied this procedure for one reason or another.

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