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Down syndrome: Parental strategies for stress among cultures

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DOWN SYNDROME: PARENTAL STRATEGIES FOR STRESS AMONG CULTURES

A Project

Presented to the

Faculty of

California State University,

San Bernardino

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

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by

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ABSTRACT

Parenting a child is a difficult and stressful job. Children are constantly changing their behaviors which can lead to frequent increases of stress in parents. The purpose of this research was to examine the perceptions of parents of different cultures on how to cope with stress in relation to caring for a child with Down syndrome (DS). Convenience sampling was used because the researchers went to support groups to recruit participants. The sample of participants consisted of nine Caucasian, eight Latino, and three multiethnic mothers for a total of twenty.

The study found that participants that attended support groups had a high level of education and income. The number one coping strategy used by respondents was prayer and religion. The biggest challenges were the school system and communication with the child. There were no significant cultural differences found. It seemed that parents with children with DS form their own culture within themselves in order to gain support and knowledge from each other.

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DEDICATION

First, I would like to dedicate this thesis to my husband, Juan, my daughter, Crystal, and my mother Margarita. I could never thank you enough for all your support and understanding. Then, I would like to dedicate this thesis to the people that believed in me. I would like to say that the words of encouragement and the support these people provided me is the number one reason I am here today celebrating this achievement. I would like to say that I did not do this by myself. I had a great team beside me all the way through this arduous and rewarding journey. In addition, this has been a learning experience for my family and me. I am the first one to graduate from high school and attend college. Now, I will be the first one to have a graduate degree. Therefore, I would like to dedicate this thesis to my family. I hope my achievements will open the door to education for the generations that follow. I would like to thank my family members for their understanding when I was not able to attend the quinceñera, baby showers, birthday parties, or visit the newborn babies.

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To my best friend, my brother, who should know that I love you very much. Always remember you can do anything you wish for; you are a strong young man. Know that if you dedicate yourself to anything you will accomplish it. Always know I will be here for you, whenever you need it.

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CHAPTER ONE

INTRODUCTION

Problem Statement

Parenting a child is a difficult and stressful job. Children are constantly changing their behaviors which can lead to frequent increases of stress in parents. Parenting children with disabilities can be more stressful because these children are not only displaying the typical behaviors of their developmental stage, but they may have communication and medical issues as well. Parents also are dealing with other stressors like doctors' appointments, defiant behaviors, health issues, communication difficulties, and not being potty-trained. As a result, the stress these parents are dealing with may lead to child abuse, neglect, or maltreatment if the parents do not have a way to cope.

According to Horejsi (2001), the social work profession earlier in its history did not demonstrate competence or interest in the mental retardation field. This lack of competence and interest was reflected in the lack of publications between 1956 and 1975 in the social work profession regarding mental retardation. Moreover, "society has tended to view retarded persons as less than human. The institutionalized persons, in particular, have been subjected to oppression and discrimination" (Horejsi, 2001, p. 43). There are specific periods in time in which the rights of people with disabilities were overlooked, and other periods where their rights were a priority for political discussion, such as when President Kennedy was in office.

It is important to state that during the period in time to which Horejsi (2001) referred, lack of social work competence for people with disabilities is demonstrated by the fact that this population was then placed in institutions where they stayed for the rest of their lives. During this era, people with disabilities did not have the opportunity to show society what they were capable of accomplishing.

In response to this practice, in 1975 the Lanterman Mental Retardation Act was enacted establishing the regional center system in California for providing services to people with developmental disabilities (Altshuter & Kopets, 2003). The Lanterman Act mandates that all handicapped children, as these children were then designated, receive special education and related services designed to meet their needs. This Act mandates that children with disabilities have free and appropriate public education (FAPE) that needs to be provided in the least restrictive environment (Altshuter & Kopets, 2003).

In addition, this Act mandates that an Individual Educational Plan (IEP) for each child in special education needs to be created. The IEP needs to be reviewed and rewritten every year to make sure that a child is meeting his/her educational goals (Altshuter & Kopets, 2003). In 1990, the Lanterman Act was reauthorized as the Individuals with Disabilities Educational Act (IDEA). Each state developed its own policies to make sure it complies with IDEA. IDEA guides how states and school districts provide special education and related services to children with disabilities (Altshuter & Kopets, 2003).

The protection of children with disabilities has been growing in recent years. Children with disabilities are no longer excluded from society as in the past. However, there is still a lot of room for advocating on behalf of this population. Parents of children with disabilities need to have the opportunity to give their insight about their ways of coping when raising a child with special needs.

Purpose of the Study

The purpose of this research was to examine the perceptions of parents of different cultures on how to cope with stress in relation to caring for a child with Down syndrome (DS). The findings may thus help improve information in order to provide better services to help parents deal with their stress. Such information may also formulate further hypotheses for subsequent research and may enrich programs geared towards helping parents from various cultures raising children with DS.

Although there is much research that points out parents with DS children have lower stress compared with those of other disabled children, there is not enough research that points out the strategies parents of children with DS put into practice when coping with the stress of raising a child with special needs.

To address this deficiency, this study used qualitative research to gather information about the perceptions of parents on coping with stress in their daily routine. The data collection was based on face-to-face and phone interviews. The target populations were Latinos and Caucasians. Participants, in this qualitative study, were afforded the opportunity to elaborate on issues involving parenting a child with DS. Participants also had the opportunity to bring to the study their personal perceptions and experiences, which was the purpose of the study.

This study targeted parents that attend Down Syndrome Association of Los Angeles (DSALA) support groups. DSALA has support groups for parents all over Los Angeles, Riverside and San Bernardino Counties. Therefore, the sample for the study was purposeful because the study was only focused on parents that have children with DS and attend the DSALA meetings. In addition, this sample was a convenience sample because the parents in the support groups were easy to find and they were available to the study since the researchers attended the support groups to seek participants to conduct the research study.

Significance of the Project for Social Work

It is important to look at and talk to parents about stress because they are the ones experiencing it on a daily basis. Parents have different ways of copying with stress and they can educate other parents about this topic. Stress is a problem that needs to be understood because of the risk that children with disabilities have of being abused. There are many things that contribute to child abuse and stress could be one of them. It is important to have a clear picture of how much parents know about ways to cope with stress to develop better services for these parents. Children with disabilities are a vulnerable population, and the families may deal with a lot of stress when there is a disabled child in the home. These families need to understand how important it is to learn strategies to deal with stress, and one way to teach these families about stress is to find out how they are coping with stress now and then to provide them with better coping resources for their future.

Thus, it is important to learn about the ways parents of children with DS manage their stress. This matter is a concern to DSALA, regional centers, and Department of Children's Services (DCS). Providing these agencies with information may contribute to their knowledge and training to help families raising children with developmental disabilities.

The issue of stress and the ways parents cope with it has always been a topic for discussion. Parents worry that they do not have the resources they need to cope with their stress. The groups of parents that run DSALA have a concern about the stress parents' deal with and offer workshops on how to release stress. Regional centers and DCS personnel offer respite for parents to help them decrease their stress by getting away for a couple of hours. The one thing all these people have in common is their concern about the stress parents are dealing with at home. Therefore, this study intends to ask parents directly to talk about the ways they cope with stress. This research may open the door for communicating directly with the parents on an important issue like stress.

This research design involved three phases of the generalist intervention model: engagement, assessment and implementation. The researchers engaged with parents of children with DS, in order to establish rapport with these parents so that they can voice their opinions about the stress involved in their lives in reference to raising a children with DS. After all the data was collected, results were assessed as to what the needs are among the groups interviewed. Implementation of programs or services geared to helping parents deal with stress was the objective of the study.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter covers the history of Down syndrome (DS) in detail to better understand the populations being studied. The information includes characteristics of DS and its history. Then, parental stress is defined and the discussion leads to the effects that it may have on the family structure. After that, the discussion pursues the cultural aspects of the population and the different strategies parents of different cultures use to cope with stress. This chapter ends with the theoretical approach that guided this study.

History

DS was discovered by John Langdon Down in 1866. He described DS characteristics and distinguished DS from other conditions by noting common physical features such as straight thin hair, small nose, and a broad face. Down was responsible for naming the condition "mongolism." Those who had it were called "mongoloids" or "Mongolian idiots." It was not until the 1960s that those terms were protested against by Asian people along with the parents of children with DS. In response, "the medical community chose to name the condition Down's syndrome in honor of John Langdon Down. Later the final "s" was dropped to become the term "Down syndrome" used today" (Girod, 2001, p. 14).

Down Syndrome

According to the National Down Syndrome Society (NDSS) (2007), "Down syndrome affects people of all ages, races and economic levels. It is one of the most frequently occurring chromosomal abnormalities found in humans, occurring once in approximately every 800 to 1,000 live births" (p. 1).

DS is a genetic disorder that is caused by abnormalities in a person's genes. Merriam Webster's Medical Dictionary defines Down syndrome as a "congenital condition characterized by moderate to severe mental retardation, slanting eyes, a broad short skull, broad hands with short fingers, and by trisomy of the human chromosome numbered 21 called also Down's, trisomy 21" (2002, p. 3). The American Psychiatric Association (1995) Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) does not discuss DS except for a passing mention during the discussion of how to rate different degrees of mental retardation on Axis 2. In the DSM-IV DS is on page 877 under code 758.0 because DS is a chromosomal abnormality.

Persons with DS have an extra chromosome, for a total of forty-seven in each cell instead of the usual forty-six. The extra strand is chromosome number 21, meaning that instead of the normal pair; there are three copies of chromosome 21 in each cell. This led to call the condition trisomy 21 (tri-meaning three and -somy for chromosome) which changes the body's and brain's normal development (Girod, 2001).

Even though people with DS have an extra number 21 chromosome, all of their other chromosomes are normal. According to Stray-Gunderson (1995) "The material in the number 21 chromosome is normal as well; there is just too much of it" (p. 10). The additional material causes a genetic imbalance and thus changes the normal course of development. What causes DS and why chromosome 21 sticks together is still unknown. The only determining factor related to the likelihood of having a baby with DS is the mother's age. According to NDSS conceiving a child with DS increases with age; a woman 35 years old has one in

350 chance, and by age 45, the incidence of having a DS child has increased to one in 30 (Dewey, 2007).

There are various characteristics that can be associated with having DS. Physical characteristics include low muscle tone in which the muscles appear to be relaxed. Low muscle tone can affect the ability for movement and cause minimal strength in the muscles. Facial features also show DS characteristics, such as a nose in which the nasal bridge is flatter and smaller than usual. The eyes appear to slant upwards like an almond shape (Dewey, 2007). The mouth can be small and shallow; the tongue may stick out and could possibly appear larger in relation to the mouth. The shape of the head of a DS person might be smaller than a normal sized head and often times flatter, and the neck might appear thick and short (Stray-Gunderson, 1995).

Medical problems that can be associated with DS are heart disorders, vision and hearing problems, a rare type of leukemia, thyroid problems, missing or misaligned teeth, and metabolic irregularities (Stray-Gunderson, 1995).

Stress and Down Syndrome

As previously discussed, children with disabilities are at a higher risk of being abused than children without a disability. The Child Welfare Information Gateway (2001) stated that it is difficult to estimate the rates of maltreatment among children with disabilities. One of the reasons is the way each state collects their data on children with disabilities. Even though maltreatment is generally defined using the Federal Child Abuse Prevention and Treatment Act (CAPTA) and disability is defined using the Federal Americans with Disabilities Act (ADA), there is still difficulty in getting researchers and states to collect data in the same way in regards to maltreated children.

Cooker and Standen (2002) stated that children with disabilities are at risk of being abused; however, children that have multiple disabilities appear to be at a higher risk of being abused and neglected. In addition, there is no reliable information on the number of children with disabilities who are being abused. According to the Child Welfare Information Gateway (2001) it was found in 1997 that children with disabilities were 3.4 times more likely than children without disabilities to be maltreated. Cooker and Standen (2002) indicated that children with disabilities were 1.7 times as likely to be abused as children without disabilities. The Child Welfare Information Gateway (2001) estimated that approximately 175,000 to 300,000 U.S. children with disabilities are maltreated each year, and in the United States, nine percent to fifteen percent of all children have a disability of some kind.

Children that have disabilities encounter challenges when trying to report that they are being abused. Some of these challenges include but are not limited to communication. Children with disabilities have a limited ability to communicate information about the abusive incident. Second, if the child is able to communicate, he/she may not be taken seriously when making allegations of maltreatment. In addition, in some cases it may be difficult for professionals to distinguish behaviors or injuries that are a result of abuse and neglect from those that may be cause by the disabilities themselves(Mitchell, Turbiville, & Turnbull, 1999).

Parents and families of children with disabilities are faced with many stressful challenges. Abery (2006) defined family stress "as a state that arises from an actual or perceived imbalance between the demands placed on a family and the family's capability to meet these demands" (p. 4). Moreover, when the family does not have the ability to handle additional demands in their environment this can become an extra stressor on the family system which puts children with disabilities at high risk for abuse. It is important to state that when parents/caregivers experience high stress levels the chances for children with developmental disabilities to be abused increases. Moreover, not all members of this population who raise a child with DS have the tools they need to care effectively for these children (Petr & Barney, 1993).

Parents that have children with developmental disabilities are frequently faced with guilt, depression and marital distress in the first months after the child is born. This can lead to maladaptive behaviors (Pelchat, Ricard, Bouchard, Perreault, Saucier, Berthianume, & Bisson, 1999). Moreover, the concept of developmental disabilities is fairly new; it originated in the early 1970s (Horejsi, 2001). It is important to point out that the terms mental retardation and developmental disabilities are commonly used interchangeably. Even though individuals who are mentally retarded are developmentally disabled, this does not necessarily mean that all individuals that are developmentally disabled are mentally retarded (Pelchat et al., 1999).

Hodapp, Fidler, and Ricci (2001) stated that when comparing parental stress among children with different developmental disabilities, parents that have children with Down syndrome may experience less stress. However, Hodapp et al. (2001) found that when comparing the stress levels of parents of children with DS to parents of normally developing children, the results were different. The parental stress was higher in parents that had children with DS than on parents with normal children.

Hastin, Thomas, and Delwiche (2002) studied the relationship between parental stress and grandparent support. This study found no difference between mothers and fathers living in the same home when looking at their reports of stress and their rating of support with grandparents. Furthermore, the study stated that maternal grandparents are more likely to provide support than the paternal grandparents. In addition, grandmothers are more helpful than grandfathers, and those grandparents that live closer are more likely to be more supportive of the parents of children with disabilities than grandparents that live far away.

Ricci and Hodapp (2003) looked at fathers' perceptions of stress and involvement with children with DS compared to fathers of children with other developmental disabilities. It was found that fathers of children with DS experience less child-related stress than fathers of children with other developmental disabilities. In addition, fathers of children with DS reported less stress in terms of the child's "acceptability, adaptability and demandingness" (p. 280). Interestingly enough it was found that participants in the study had almost identical involvement in their daily paternal interaction with their children.

Stores, Stores, Fellows, and Buckley (1998) assessed the stress of mothers of children with DS and daytime behavior and its relation to maternal stress. This study found that children with DS tended to display more problems in their daytime behavior when they were in the age groups of four-seven and eight-eleven. It was also noted that boys with DS displayed more daytime maladaptive behavior as compared to girls with DS. When referring to maternal stress, Stores, Stores, Fellows, and Buckley (1998) found that the mothers that had children with other intellectual disabilities scored higher on the stress scale than mothers of children with DS. Nevertheless, it is important not to underestimate the level of stress among mother of children with DS because these mothers' stress level scores are reaching the critical level for women with depression (Stores, Stores, Fellows, & Buckley, 1998).

Culture

It is important to have a clear definition of family and culture because family can be culturally defined in many different ways. Baker (2003) defines family as "a primary group whose members assume certain obligations for each other and generally share common residence" (p. 154). This study will look at different cultures: Latino and Caucasian. Thus, culture is "the customs, habits, skills, technology, arts, values, ideology, science, and religious and political behavior of a group of people in a specific time period" (Baker, 2003, p. 105).

Family and cultural groups can differ in many ways. They may have the same or different needs. However, the only thing that does not differ among these groups would be the fact of having a child with DS because it can and does occur in all cultural groups. However, different cultures deal with the situation differently. For instance, when comparing African American and White family caregivers of a person with developmental disabilities, the African American families were less likely to place their relative out of their home and to utilize services for the person with disabilities (McCallion, Janicki, & Grant-Griffin, 1997).

Schwartz, Rubert, and Szapocznik (2006) conducted a study among caregivers of adults with mental retardation. This study was composed of 153 primary caregivers with an age range of 41 to 87. All the participants were Hispanic. This study was investigating the stress-process model for Hispanic caregivers. The study concluded that there was a connection between maladaptive behaviors of the retarded adult and psychological distress for the caregivers. Therefore, it was stated that when the family was faced with maladaptive behavior, this could create heavier stress loads for the family to deal with.

Moreover, it was concluded that the relationship of the caregiver and the person with disabilities would reflect on the relationship of the family members. Therefore, the way the family copes with the stress of the maladaptive behaviors can cause either conflict or consensus among the family members when making decisions about how to respond to the problematic behaviors (Schwartz et al., 2006).

Schwartz et al. (2006) stated that African American caregivers used religion as a way of coping when working with a person with disabilities. African American caregivers rated the highest on religious coping when looking at caregiver satisfaction compared to Hispanic and White caregivers. The researchers continued to state that Hispanic mothers that care for a child with mental retardation were more likely than African American and White mothers to report high levels of depression accompanied by poor physical health.

McCallion et al. (1997) discussed in their study "the lower usage of formal services" (p. 348) among minority cultures and their feelings toward these services. Many minority cultures depend a lot on their family support because it is in their cultural beliefs that the family is responsible for taking care of their own. Therefore, cultural traditions and values can influence minority cultures when seeking services that can be beneficial for the family and the child with disabilities. However, this brings up issues that can affect diverse cultures in terms of services because if they do not utilize the services, they can lose them, creating fewer services for minorities.

According to McCallion et al. (1997), families from non-white cultures prefer family caregiving and not discussing their problems with strangers; they are suspicious and have low expectations of the "white culture" (p. 348) and its institutions. They have difficulty justifying the use of community services which are modern interventions and not part of cultural traditions.

Difficulty exists in accessing services for families in which English is not their first language. The focus group reported that language difficulties worsen the situation, and translating is not something they are comfortable with since much personal information is being exposed. Finding adequate or even available resources causes more stress to the families, since it makes the process of getting help or something as simple as a doctor's appointment more difficult.

Family resources such as making friends with other families with children with disabilities or joining a support group can provide a source of support. Parents have demands and strains of rearing a child with DS which can build up over time and with the child's stage of development; families must develop new resources continually that will help them meet current and future demands. "When available, these can be called upon to reduce stress, solve problems, and facilitate parents balancing the demands of rearing a child who has a disability with their capacities" (Abery, 2006, p. 8).

Theories Guiding Conceptualization

The theories that guided this study were systems and ecological theory. The combination of these theories brought to the study structure and balance. Systems theory focuses on the effective functioning of the relationships and resources between families and groups. Therefore, in a systems perspective life stressors of parents of children with DS can bring additional stress to other systems in the family or outside the family as in the community. For example, if the child with DS has a heart problem, he/she will have numerous doctor visits which can bring extra stressors to the family. Ecological theory looks at the individual in his/her environment. Ecological theory states that the individual and environment are dependent on each other. Therefore, this dependency among both systems becomes a mutual system which brings us back to the mission of social work to help people fit into their environments (Payne, 2005).

Furthermore, Payne (2005) talked about the "life model" (p. 150) originated by Germain and Gitterman. This model was influenced by ecological systems theory. This model fit the structure of this study in a conceptual way. The life model looks into the life path of people. As people go through life they are faced with life stressors. For example, giving birth to a child is a stressor in itself for a family and the parents. However, if this child is born with developmental disabilities the family will be encountering extra stressors like those in the population being studied. This family is going to be faced with unexpected disturbances in their ability to adapt to their environment making it difficult for them to cope with their situation.

The life model states that people in these situations go through two different stages. The stages are appraisal of the stressor and the stress, as stated by Payne (2005). The parents first look at the severity of the issue and how it is going to affect them. Then, the parents look at the strategies they need to cope with the situation, and the resources they may have to help them cope. Some parents will try to cope by changing something in their environment, in themselves and in their emotions. At this point parents are putting all the efforts they can into coping with their situation (Payne, 2005).

The purpose of this model is to help people create a better fit between themselves and their environment by reducing life stressors. This model wants people to increase their personal and social resources and to put into practice better coping strategies which will influence their environment. This model has a strong association with the purpose of this study (Payne, 2005).

Summary

This chapter gave an extensive explanation of DS symptoms. It outlined the parental stressors of raising a child with DS. In addition, it discussed how other members of the family cope with stress. In this chapter the way different cultures cope with stress was also discussed. Last, the theoretical approach that guided this study was discussed.

CHAPTER THREE

METHODS

Introduction

This chapter discusses the design of the study which was a qualitative approach. It also focuses on sampling, data collection instruments, the procedures that were followed for protection of human subjects and analysis of the data.

Study Design

The purpose of this research was to examine the perceptions of parents of different cultures on how to cope with stress in relation to caring for a child with Down syndrome (DS). This study gave parents the opportunity to talk about stress and their different coping strategies. Parents are the ones experiencing the stress on a daily basis making them knowledgeable on this subject; therefore, they are an ideal target for this study.

A qualitative research study was designed which included personal and phone interviews addressing the parental perceptions of coping strategies in the Latino, and Caucasian cultures, in conjunction with gathering other demographic information in a questionnaire format. The qualitative approach provided participants with the opportunity to bring to the study their personal experiences.

Some limitations to the study are that the results cannot be generalized to the way parents cope with stress when raising a child with other developmental disabilities. Also, the data was gathered from parents attending support groups; therefore, the perceptions of parents not attending support groups might be different. The research question of this study was: What are the perceptions among different cultures of coping strategies of parents with children with Down syndrome?

Sampling

This study used purposeful/convenience sampling. Purposeful sampling was used because the target participants are knowledgeable about the study subject. Convenience sampling was used because the researchers went to support groups to find the participants. The purpose/convenience sample of participants consisted of nine Caucasian, eight Latino, and three multiethnic mothers for a total of twenty interviews. The participants were selected by posting signs and distributing flyers inviting Latino and Caucasian parents with DS children to volunteer to participate in this research study (Appendix, A). Signs were posted on the bulletin board of seven support groups of the Down Syndrome Association of Los Angeles (DSALA). The support groups are in Los Angeles, Riverside and San Bernardino Counties. The flyers were distributed at their monthly meetings by the researchers with an explanation and invitation to participate in the study. The flyers had a number for people interested in participating to call to set an appointment with the researchers.

DSALA is the leading Down syndrome (DS) non-profit charitable organization of families and professionals in Southern California supported by tax-deductible donations and fund raising activities. DSALA is committed to improve the well being of people with DS and their families through the progress and encouragement of education, counseling, employment and recreational programs. DSALA sponsors support groups in the area to help parents maintain a support network. In addition, DSALA advocates for appropriate educational services for children with DS. This organization has a commitment to increase public awareness to bring understanding and acceptance of people with DS.

Data Collection and Instruments

The study utilized two instruments to collect the data. One of the instruments was a Demographic Questionnaire (DQ) (Appendix, A), and the second was an open-ended Personal Interview Questionnaire (PIQ) (Appendix, B). These two questionnaires are administered by the interviewers. Both of the instruments were available in a Spanish version, for the participants that were unable to use the English version.

The DQ instrument was designed to collect demographic information. The strengths of the instrument are that it provided background information on the participants to identify and categorize the demographic data.

The PIQ was designed to help as a guide for the interviews. The PIQ is composed of open-ended questions. The questions that are included in this instrument were designed to collect information on the way parents cope with the daily stress of caring for a child with DS, parents' challenges, parents' support system, religious influence when coping with stress, and outside support. One of the questions in the study addresses parents' suggestions to other parents who are raising a child with DS. This allowed the participants to express their views to other parents that are in similar situations.

Since both of the instruments used in the study were newly developed, a pre-test was conducted with five parents of children with DS, three Latinos and two Caucasians. The participants in the pre-test were recruited on a voluntary basis to provide feedback as to the validity of the IQ and PIQ as they apply to the research question. The interviews completed in the pre-test were not included in the data analysis.

Procedures

Contact was made with one of the parents in charge of the support group from DSALA, located in Pomona. The researchers contacted seven different support groups from DSALA during the process of seeking participants.

The data was gathered by interviewing the parents that meet the criteria of the study sample that attend DSALA support groups. The sampling criterion was that the parents have a child with DS and their cultural background is Latino or Caucasian. Participants were given an incentive to participate consisting of a ten dollar gift card to their choice of Target or Starbucks. The interviews were recorded on audiotape and hand written notes were taken at the time of the interviews.

An introduction was given to the parents about the purpose of the study. Upon giving their consent to participate in the study, participants were given the opportunity to set up an appointment for their interview before or after their support group as well as other times. The interview took place in a closed area, or by phone to provide confidentially to these participants.

The interviews were conducted in the preferred language of the family (English or Spanish). Both interviewers are bilingual. Interviews were conducted with both interviewers being present for safety and reliability purposes.

Protection of Human Subjects

The researchers complied with all the rules and regulations required by the Institutional Review Board of California State University San Bernardino. No names were taken from participants and the audio recording and hand written notes collected were destroyed after the study was completed to ensure confidentiality. Participants were provided an informed consent (Appendix, C) as well as a debriefing statement (Appendix, D) in order to ensure they were knowledgeable about the purpose of the study. The Code of Ethics of the National Association of Social Workers (NASW) was strictly followed throughout the study.

Data Analysis

For the purpose of this study various steps were taken in order to analyze the qualitative data. The data collected during the interviews had emerging themes. After all the data was collected, the researchers looked over the material collected and listened to the recorded audio in order to become more familiar with the data set. The researchers then used coding in order to analyze the data. By coding the data it helped to identify the differences and similarities in the findings and facilitate data categorization.

Coding of the data proceeded in stages and each stage was several steps. The first stage of coding was concrete, which was to categorize properties of the data that are evident to the researchers. Concrete coding was a lengthy process which involved five tasks: identifying meaning units, assigning category names to groups of similar meaning, assigning codes to categories, refining and reorganizing coding, and deciding when to stop (Grinnell, 2005).

In concrete coding the researchers were able to identify important data and classify them into segments by putting the data into either single word, partial or complete sentences or a paragraph. Categories were then formed to organize the data. The categories were developed or changed during concrete coding. Codes were assigned to the categories which is a shorthand method of identifying the data. Refining and reorganizing took place in order to ensure that the analysis reflects the research conducted.

Summary

This chapter outlined the design of the study along with the sample population from which information was obtained. It also described the development of two instruments to collect the data and how the information was analyzed. In the study, the protection of human subjects was a main concern and the steps necessary to provide confidentiality have been discussed.

CHAPTER FOUR

RESULTS

Introduction

This chapter presents the findings of this study regarding the coping strategies used by parents of children with Down syndrome (DS). Demographic information is presented in independent variables: ethnicity, age, education, employment, primary language, marital status, and household income, to provide information regarding the population studied. The findings of the qualitative data found throughout the questionnaires will be discussed.

Presentation of the Findings

Participants consisted of twenty mothers of children with DS who were involved with Down Syndrome Association of Los Angeles support groups during the administration of the surveys.

The participants identified themselves as follows: nine Caucasian, eight Latino, and three multiethnic. Of the multiethnic participants one participant identified herself as being Caucasian and Latino, and the other two identified themselves as being Caucasian and African

Table 1. Mothers' Ethnicity, Age, Employment Status and Education

Variable	Frequency	Percentage
Ethnicity		
Caucasian	9	45%
Latino	8	40%
Multiethnic	3	15%
Age		
24-35	4	20%
36-40	5	25%
41-44	4	20%
45-51	7	35%
Employment		
Employed	12	63%
Not employed	7	37%
Work Status		
Full-Time	9	75%
Part-Time	3	25%
Education		
Less than High School	1	5%
High School Diploma	3	15%
Some college	8	40%
Bachelor's Degree	3	15%
Graduate Degree or Higher	5	25%

American. The ages of the mothers ranged from 24 to 51 years old. The mean age of the mothers is 41 with the largest group of the mothers being 45 to 51, which was 35% of the total sample. Approximately, 63% of the mothers were employed, and 37% were not currently

Table 2. Fathers' Ethnicity, Age, Employment Status and Education

Variable	Frequency	Percentage
Ethnicity		
Caucasian	8	58%
Latino	11	37%
Multiethnic	3	5%
Age		
29-36	4	18%
37-40	5	30%
41-50	9	53%
Employment		
Employed	15	83%
Not employed	3	17%
Work Status		
Full-Time	14	93%
Part-Time	1	7%
Education		
Less than High School	1	5%
High School Diploma	3	17%
Some college	13	73%
Bachelor's Degree	1	5%
Graduate Degree or Higher	0	0%

employed. Of the mothers that were employed, 75% worked full time and 25% worked part-time.

Of the respondents, 49% had received some college education; 25% of the respondents had completed college or higher; 15% had Bachelor's degrees; 15% had a high school diploma; and 5% percent of the respondents had less than a high school diploma.

The fathers' ethnicity as reported by the mothers was as follows: eleven Latino, seven Caucasian, and one African American. The fathers' ages varied from 29 to 50 years of age, and the average age of the fathers was 43 years of age. The largest age group of the fathers was 46 to 50, which was 53% of the total sample. Over 83% of the fathers were currently employed; 17% were not employed. Among the fathers that were employed, 93% worked full-time and 7% worked part-time.

Table 3. Children's Ethnicity, Age and Gender

Variable	Frequency	Percentage
Ethnicity		
Caucasian	6	30%
Latino	8	40%
Multiethnic	6	30%
Age		
29-36	8	40%
37-40	5	25%
41-50	7	45%
Gender		
Female	11	55%
Male	9	45%

Of the respondents 73% of the fathers had some college; 17% of the fathers had a high school diploma; 5% had a bachelor's degree; and 5% had less than a high school diploma.

The ethnicity of the children was as follows: nine Caucasian, eight Latino, and six multiethnic. The sample consisted of eleven females and nine males. The age of the children ranged from 1 to 20 years old, and the average age of the children was 9 years old.

Table 4. Respondents Primary Language, Marital Status and Household Income

Variable	Frequency	Percentage
Primary Language		
English	18	90%
Spanish	2	10%
Marital Status		
Married	16	80%
Divorced/Separated	3	15%
Single	1	5%
Household Income		
$10,000-$25,000	1	5%
$25,001-$40,000	1	5%
$40,001-$55,000	4	20%
$55,001-$70,000	6	30%
$70,001-$85,000	4	20%
Over $85,000	4	20%

Of the participants, 90% reported that English was their primary language, and 10% reported Spanish as their primary language. The reported marital status of the participants was 80% were married, 15% divorced or separated, and 5% single.

Combined income for the respondents revealed that 30% made $55,001-$70,000; 20% of respondents made over $85,000; 20% made $70,001-$85,000; 20% made $40,001-$55,000; 5% made $25,001-$40,000, and 5% made $10,001- $25,000.

The participants were asked several questions in relation to raising children with DS. The first question asked how respondents cope with the daily stress of caring for a child with DS. Six respondents reported that they cope through prayer and religion which was the most frequent response. They indicated that by praying and putting their worries in God's hands, they believed it helped with their daily stress.

Five respondents emphasized the importance of having family support. One respondent said, "My family is really supportive. If not I don't think I can do it as well; they all help." Four respondents emphasized how important it is to have couple support and communication. A strong teamwork can help share the stress among each other and share their frustrations with each other.

Respondents also expressed the need for an established routine which helps them get through the day. One respondent stated, "Having the children in bed by 8:00 makes a big difference. That way I have time to relax and get me ready for the new day." Some of the other responses on how to cope with the daily stress were by organization, support from other parents with DS children, advocating for the child's school rights, self care, working, education about DS, professional support, support groups, children being more independent, acceptance of DS and support from friends.

Among the Latino respondents, most reported that religion and routine was how they cope with the daily stress of caring for a child with DS. With the Caucasian respondents family and couple support was the best way of them coping with the stress of caring for their child with DS.

The second question that was asked was what was or currently is their biggest challenge in raising a child with DS. The highest given response shared by seven parents was that the school system is the greatest challenge. One respondent stated, "School. Fighting for the appropriate services. They don't just give them to you even if they are available. You need to fight for them." Another respondent said, "The school has given up, and I guess that's my biggest stress right there. They don't know to deal with him." Six respondents felt that communication with their child was the biggest challenge. One respondent said, "The fact that she can't talk, she can't tell us what she wants or needs and she can't tell us when thing aren't going well." They expressed that because of speech delays and not only trying to find out what the children want but in figuring it out correctly causes great challenges. Four respondents reported that a challenge is in integrating their child into society, in hopes that their child is accepted for who they are. The respondents also expressed the following challenges such as managing their child's health problems, dealing overall with DS, managing everyday tasks, social interaction, DS children having no sense of safety, behavioral issues, dating, motivating them and having insufficient energy.

For this question Latino respondents reported that communication with their child and the school system as being the biggest challenges in raising a child with DS. Caucasians had similar responses; most reported that integrating their child into the world and the school system as being big challenges.

The third question given to respondents was what has been the most helpful for them when coping with the stress. The biggest response given by five participants was their relationship with their family. They indicated that by having the support of their family and the ability to rely on them when needed helped them cope with stress. Religion, support from other parents with DS children, educating oneself about DS, acceptance of DS and support groups were among the next most given responses. The respondents felt that by their relationship with God, support from other parents who have children with DS, especially those who have gone through similar experiences, empowering themselves to find what is available and making themselves self informed, accepting of DS instead of fighting it or being in denial and the support groups that provide them with useful information were the most helpful in coping with stress. Other responses that were given were self care, having their DS child home schooled, spousal support, professional help, interaction with other children with DS and being optimistic helped in to cope with stress.

The fourth question asked respondents to talk about their support system in relation to raising their child with DS. Sixteen respondents said that their family has been a great support system. One respondent stated, "My family has been a tremendous support and encouragement." Another one said, "My family is very supportive as far as getting her ready or helping me in parenting." Then ten respondents stated that spousal support helps tremendously. As one respondent stated, "My husband knows when to kick in when I am up to my neck with the stress." Another respondent stated, "My husband has understood her in the way of how active she is and how exhausting it is for me to keep up with her." Six respondents said that support groups have been a great support system. Having the support group informed them of the services available for DS children, giving suggestions and sharing experiences of each others' children. Five respondents believed that their church was a highly beneficial support system because of prayer and by providing the families with their faith which helps them cope. One respondent stated, "My church. I will be honest with you.

They are amazing. They treat her just like everyone else." Friends, having a day care provider, regional centers, professional support, other parents with DS children, community support and self education were also among other given responses.

Latino respondents indicated that family and regional centers were their greatest support in raising their child with DS. Caucasian respondents' most given response was that their support system consisted of family, spousal support and other parents raising children with DS.

Question number five asked respondents about who in their support system has been the most helpful in coping with their DS child. Nine respondents reported that their family was the most helpful support system they had. One respondent stated, "The most supportive has been my family and my husband's parents. Just having people that knew us and care about us who were willing to get involved and say what we can do to help." Five respondents indicated support groups as the most helpful. They believed that the groups provide them support, good advice, connection with people who can help and words of encouragement. Five other respondents discussed that regional centers were the most helpful in giving them the support needed. The respondents expressed that Inland Regional has provided them with the resources and information needed, as well helping them navigate through the system. Four respondents reported that the greatest support system they have is the support of other parents who have children with DS. As one respondent said, "A mom from the support group lets me just hang out with her and her son, and she wasn't pushy. She really listened to me a lot. She help me weave through things." Other responses were help from professionals, spousal support, prayers and religion, friends, knowledge and education.

Question number six asked respondents to describe how that person(s) has been helpful. Sixteen respondents said that they have given them the support and help necessary to raise a child with DS. A respondent stated, "They came alongside and got to know my family and my daughter and they were just there when I needed them." Another said, "By helping with day to day things we take for granted from cooking dinner or doing laundry." Six respondents stated that they had been helpful throughout by empowerment and encouragement. One respondent stated, "Encouragement. The recognition from other people that your child is more than just a label of DS and that they are this fully developed person who this just happens to be a small part of." Other responses were that networking with other families who had children with DS has been helpful as they understand what they are going through. Furthermore, some respondents said that by other people praying for them and their family and helping them find the needed resources was what their support system did in order to be helpful to them.

For question number seven the respondents were asked to discuss what stressors, if any, they felt were added to their lives when their child with DS was born. Seven respondents stated that it was just overwhelming raising a child with DS. One respondent said, "Trying to balance everything and not to get burnout. It takes a lot of patience to raise a child with special needs." Not knowing what to expect when raising a child with DS, and all the demands DS requires without knowing what to do at times was discussed. Another respondent stated, "Because I had to take care of her, and not knowing about DS, I thought she was going to be mentally retarded and that was a stress for me." Five respondents stated that emotional stress was added to their lives. Other responses accepting the fact that this is how their life is going to be from now on, or not knowing how to cope with having a child with special needs and at many times having to stop everything in their lives and focus all their attention on their DS child. Another stressor in which four respondents reported as significant was their DS child having health issues. One respondent stated, "She has heart issues, and doesn't eat well. She has got two major surgeries and that has been really stressful. There were weeks in which we didn't know if she will live or die and that was really hard." Four respondents talked about the need to teach oneself about DS as a stressor. They felt that they needed to educate themselves in order to get the appropriate services they want to provide their child with what he/she needs, and to learn to get services because frequently they are not offered. The other stressors that were added to the respondents' lives when their DS child was born was the community's lack of understanding about DS as well as financial issues that arise because many parents had to quit working to take care of their child. Other respondents discussed the stressors of the education of their children and the respondents being worried about their child's future such as if they will be able to take care of themselves if the parents are not longer alive, and, lastly, in dealing with regional centers, and finding adequate professionals who can help their child with DS.

When comparing what the Latino and Caucasian respondents felt what stressors were added to their lives' when their child with DS was born, Latinos indicated that it was overwhelming raising a child with DS and finding adequate professionals. Caucasian respondents also believed that it was overwhelming raising a child with DS and they worried about their child's health.

The eighth question asked respondents if religion/spiritually/prayers contribute to their emotional well-being or help to reduce their stress in raising their child with DS. Seventeen respondents said that religion, spirituality and praying help them reduce their stress, such as, having God in their lives helped provide them with support and peace. Some indicated that through praying and knowing that things happen for a reason and they are blessed to have a child with DS, helped them feel better. They also indicated that they begin to focus more on the child's positives. The programs at church helped. It was a form of meditation and they started to appreciate what was given to them. One respondent stated, "Absolutely. Just by recognizing that our son is a gift from God, we all like to be surprised by gifts and sometimes you are expecting one kind of gift and then you get something else and you discover this is what the perfect match was. The other thing wouldn't have really mattered." Three respondents stated that neither religion, spirituality or prayers helped reduce their stress. The Latino and Caucasians respondents both believed that religion, spiritually and prayers contributed to their emotional wellbeing in raising their child with DS.

Latinos and Caucasians believed that by religion being part of their family's lives it provided them support, peace and knowledge that everything happens for a reason, and they felt blessed.

Question number nine asked respondents what resources, services or organizations helped them better deal with their DS child. Fourteen reported that Inland Regional Center helped by providing respite workers, intervention at an early age, getting a medical waiver which provides them with a nurse and IEP meetings. Twelve reported that support groups were helpful as they have mom's night out in which they can network and talk about things they deal with and also help provide them with information. Five respondents discussed how DS literature was vital. One respondent said, "My greatest resources came from the multitude of written literature." Other given responses to helpful resources included church, school, knowledgeable professionals, conferences, and county programs. They also noted that other parents with DS children and programs through Kaiser were helpful resources which assisted them in better dealing with their DS child.

The tenth question asked the respondents if they had any comments that would be helpful in raising a child with DS. The most frequently reported responses that were given were to find people to communicate, get support and help from. One respondent said, "You need to find people that you can communicate with, what is your heart's desire for your child and then keep asking around to find the person who can help you get it." Another comment was to learn as much as you can about DS. One respondent discussed, "To learn as much as you can to help yourself so you can be healthy to take care of a child with special needs." Some respondents believed that parents with DS should not underestimate the DS child's abilities. As one respondent stated, "Never underestimate your child. Never think that you are wasting your time in working with them on this or letting them explore this. Let them try everything they show an interest in and expose them as much as you can as early. Don't ever be ashamed to take them anywhere in public." Other comments the respondents wanted to share with other parents raising children with DS were to take it day by day, accept your child for who they are, never give up on them, enjoy your time with them and to get early intervention for your child.

Summary

This chapter presented the findings of the study in great detail. The findings included demographics of the sample population from which information was obtained as well as the result from the personal interviews. This study found the majority of the participants came from a high income level. The results indicated that 30% of the respondents had household income ($55,001-$70,000). Prayer was found to be the most common way of coping with the daily stress of caring for a child with DS. On the other hand, communication and the school system were identified by participants as being the most challenging stressors they dealt with. The study found that respondents felt that family support was very important when raising a child with DS, as well as spousal support and communication among these systems.

CHAPTER FIVE

DISCUSSION

Introduction

The following chapter presents discussion of findings of this study. This chapter also discusses the limitations of the study. The chapter concludes with recommendations for future social work practice, policy and research.

Discussion

The purpose of this research was to examine the perceptions of parents of different cultures on how to cope with stress in relation to caring for a child with Down syndrome (DS). The findings concluded that 40% of the mothers that participated in this study had some college and 25% had a graduate degree or a higher education. In addition, combined household income reported by the mothers was that 30% earned between $55,001 and $70,000 and 20% earned $85,001 or over. Therefore, it was concluded that most participants that attend support groups have a high level of education and income (See Tables 1 and 4).

Furthermore, it was found that when coping with the daily stress of caring for a child with DS the number one coping strategy used by respondents was prayer and religion. Though, it is important to acknowledge that not all participants felt that prayer or religion was a part of their lives. However, prayer and religion seemed to play a big role in most of the participants' lives as it was discussed throughout the entire interview. Participants felt the need to apply prayer and religion to most of the questions asked. In addition, it was found that it was peaceful for families to have the connection with their religious beliefs. It was also found that prayer and religion was a big support in their lives when coping with their stress of caring for a child with DS.

The findings of the study have shown that the biggest challenges of the participants in raising a child with DS were the school system and communication with the child. It was found that participants that struggled through the school system defined the experience as a stressor in their lives. From the participants' responses it was gathered that children with DS need extra help in school such as speech therapy, occupational therapy, and physical therapy. From the participants' perspective it was found that school districts did not provide services to children automatically; parents need to fight for their children's rights through an Individual Educational Plan (IEP). In some cases the school districts do not offer the classes that accommodate the needs of children with DS. It was found that participants felt as if they needed to advocate for their children all the time and this became a stressor for them and their families. Participants in the study described the school system as being a bigger stressor in their lives than the child with DS. Participants reported that they did not have the energy or time to be fighting the school system because they needed to deal with other challenges such as the communication needs of their children.

It was found that when the child with DS has poor communication skills, as most do, these become a huge challenge to the participants. The issue of communication was brought out by participants as a barrier between the child, parents and society. Parents felt that communication was a factor that increased the level of stress during daily activities. The lack of communication prohibits the child with DS to be accepted into society and decreases the opportunities for social interaction with peers their same age as reported by participants.

This study found that the relationship with family was the most helpful resource for them when coping with stress. Abery (2006) also found that when family resources are available, "these can be called upon to reduce stress, solve problems, and facilitate parents' balancing the demands of rearing a child who has a disability" (p. 8). In addition, the participants identified family and spouse as their most important support system when coping with stress. Participants felt that it is vital to have a strong support system that can help the family during a crisis or just to provide respite for the parents.

The present study revealed that the majority of the participants found regional centers' services as helpful when it came to coping with their stress. It was found that the most helpful services provided by regional centers among the participants were early intervention programs. Furthermore, it was concluded that the respite services that regional centers provide for the parents were helpful because they allows parents time to get away and relax for a couple of hours.

Moreover, support groups were also found to be extremely helpful among the participants. It was found that support groups provided participants with a way to increase their knowledge about DS and network with other families that have children with DS, as well as the opportunity for the children with DS to form long term relations with other children with DS.

Overall this study found that each participant had their own way of coping with their stress of raising a child with DS. The overlapping coping strategies found were: prayer, strong support system, seeking help, increase knowledge about DS, accepting the child with DS, and not to underestimate the abilities of the child with DS.

The research study looked into cultural differences among the participants. There were no significant cultural differences found. Regardless of participants' cultures the study found no differences in the way parents dealt with stress. Instead it seemed that parents with children with DS form their own culture within themselves in order to gain support and knowledge from each other.

Limitations

Even though much progress was made through this research project, possible limitations of the study were found. One of the limitations was that the respondents were recruited through the support groups they attended. Therefore, it gave the study a parental perspective of only those who attended support groups. Another limitation that was found was that even though both husbands and wives signed up to be part of the interview process once it came down to the actual interview the wives were the ones to answer the questions. All of the conducted interviews were from the mothers' perspectives. The ages of the children with DS were too broad therefore creating another limitation. When looking at parental stress perhaps it is advisable to have the ages of the children arranged into categories, so the research could find how parents with children ages zero to five deal and cope with stress compared with children ages six to thirteen and so forth.

Therefore, more research is needed with a larger sample size of parents who have DS children but who do not necessarily attend a support group, and researchers can perhaps categorize the findings based on children's ages.

Another limitation identified was in order to accurately compare cultural differences in the way parents cope with stress of caring for a child with DS a larger sample size was needed. It would have been beneficial to interview a broader range of cultures as it might have provided more significant findings.

Recommendations for Social Work Practice, Policy and Research

The study may be beneficial for social workers and the Department of Children's Services (DCS), because it may help gain a better understanding of what the parents' needs are in regards to raising a child with DS.

The study may provide agencies, such as Down Syndrome Association of Los Angeles, regional centers or DCS who deal with DS children with information that might help contribute to proper training for workers or families in raising children with developmental disabilities. McCallion et al.(2007) discussed that administrators and policy makers must also reconsider whether current agency networks are sufficient or appropriate to reach out and serve families with a child with developmental disabilities. Crucial information the study may provide the agencies with is the importance that religion plays in the lives of the parents. Religion was used as a coping strategy and as their support system in raising a child with DS. Religion provided the families with support, peace and helped them focus on the positives aspect in raising their child instead of the negatives. Therefore, with the agencies knowing that religion and spirituality is important for the families it can make their services or workers more knowledgeable about different religions and tailor the services to integrate different religions.

The importance of close family relationships was also found to be significant to the respondents. Most of the respondents answered that their family was a great support system and offered a tremendous amount of help. The agencies can help incorporate services that make extended family members part of the services. Other studies could be done that identify the effects that DS children can have on their siblings as all the attention might be geared towards the DS child. Perhaps, services need to be provided for the family members as well because they might be experiencing significant stress.

The support groups offered the families a place to vent, gather information and be understood by other families who are experiencing the same stressors as they are in also raising children with DS. More attention should be put into developing more support groups or learning how crucial they might be to parents who are raising a child with disabilities.

Further research needs to be done to recruit parents who might not attend support groups. Since one of the limitations of the study was that recruitment of parents was done at support groups it is thus essential to gather information from parents in the community. Perhaps parents with children with DS who do not attend support groups might have a limited support network or not know of services available. The parents who attended the support group were mostly from a higher level income and might be more knowledgeable in seeking services than a low income family. Perhaps a study can be done to compare families coping strategies in raising a child with DS who have higher incomes versus those families' who do not.

Conclusions

The study was conducted to see how parents of different cultures cope and deal with stress in raising a child with DS. In examining the stressors that are associated with raising a child with DS, agencies and workers who help the family can have a better perception on how to help, either by setting up programs or advocating. One of the stressors that parents said they experienced was dealing with the school system. Therefore, agencies can unite in providing the families a stronger support to help them advocate or provide them with necessary information to get the educational rights they deserve.

The findings can provide crucial information for future studies, to look more into what can be done to help parents who have children with disabilities. Respondents believed that prayer and religion played a significant role therefore agencies can perhaps collaborate with churches to help provide a stronger support system for the families. It was seen that families were scared of the unknown at every stage of their child's life due to the fact that they had to educate themselves about a new stage and seek appropriate services to enrich their child's life.

APPENDIX A

DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire

CHILD:

1. Age: ______

2. Sex: 1. Female ______ 2. Male _____

3. Please list child's brothers and sisters and their age:

Sex (Female or Male)	Age
____________________	______
____________________	______
____________________	______
____________________	______
____________________	______

4. Ethnicity of child:
   1. Latino _______________ 2. Caucasian _______________

5. Ethnicity of Mother: 1-2 above ____

6. Ethnicity of Father: 1-2 above ____

7. Primary Language spoken at home _________________

PARENTS:

8. Martial Status:
   1. Married ________ 2. Living together ________ 3. Widowed ______
   4. Divorce/Separated _________ 5.Single _________ 6. Other_________

MOTHER:

9. Education:
   1. Less than high school diploma______ 2. High school diploma ______
   3. Some college ____ 4. Bachelors_____5. Graduate degree or higher_____

10. Age: ________

11. Are you currently employed 1. Yes___2. No ___

12. If you answered yes are you: 1. Full time______ 2.Part time______

FATHER:

13. Education:
    1. Less than high school diploma ______ 2. High school diploma ______
    3. Some college _____ 4. Bachelors ____5. Graduate degree or higher _____

14. Age: __________

15. Are you currently employed 1. Yes__ 2. No ____

16. If you answered yes are you: 1. Full time____ 2.Part time_______

17. Combined Household Income:
    1. Less than $10,000 ______ 2. $10,001 - $25,000 ______
    3. $25, 001 - $40,000 _______ 4. $40,001 - $55,000 ______
    5. $55,001 - $70,000 ________ 6. $70,001 - $85,000 ______
    7. Over $ 85, 001 ________

Cuestionario Demográfico

NIÑO:

1. Edad: ______

2. Sexo: 1. Masculino ________ 2.Femenino_____

3. Por favor ponga a hermanos/as del niño en una lista y su edad:

Sexo (Masculino o Femenino)	Edad
______________________________	_______
______________________________	_______
______________________________	_______

4. Pertenencia étnica del niño:

1. Latino _______ 2. Caucásico _____

5. Etnia de Madre: 1 o 2 de arriba_________

6. Etnia del Padre: 1 o 2 de arriba______

7. El Idioma primario hablado en casa_________________

PADRES:

8. La Posición Matrimonial:

1. Casados _____ 2. Conviviendo Juntos ____ 3.Viudo/a________

4. Divorciados/separados _____ 5. Soltero _____ 6. Otro _________

MADRE:

9. Educasion:

1. Menos de preparatodia______ 2. Diploma de preparatoria ______
3. Some college ____ 4. Bachelors_____5. Graduate degree or higher_____

10. Edad: ________

11. Esta actual mente empleado: 1. Si___ 2. No ___

12. Si contesto si esta empleado: 1. Tiempo completo______ 2.Medio Tiempo_____

PADRE:

13. Educación:

1. Menos de preparatodia______ 2. Diploma de preparatoria ______

3. Some college ____ 4. Bachelors_____5. Graduate degree or higher_____

14. Edad actual: _____

15. Esta actual mente empleado: 1. Si___ 2. No ___

16. Si contesto si esta empleado: 1. Tiempo completo______ 2.Medio Tiempo_____

17. Los Ingresos combinados de la Casa:

1. Less than $10,000 ______ 2 . $10,001 - $25,000 ______

3. $25, 001 - $40,000 _______ 4. $40,001 - $55,000 ______

5. $55,001 - $70,000 ________ 6. $70,001 - $85,000 ______

7. Sobre $ 85, 001 ________

APPENDIX B

PERSONAL INTERVIEW QUESTION

Questionnaire:

1. How do you cope with the daily stress of caring for a child with Down syndrome? (What helps you get through the day?)

2. What has or currently is your biggest challenge in raising a child with Down syndrome.

3. What would you say has been the most helpful for you when coping with stress?

4. Tell me about your support system in relation to raising a child with Down syndrome? (spouse, siblings, neighbors, church, relatives)

5. In your support system who has been he most helpful for your family in coping with your Down syndrome child? (spouse, siblings, neighbors, church, relatives)

6. How has that person/s been helpful to your family?

7. What stressors do you feel were added to your life when your child with Down syndrome was born?

8. If applicable, do religion/spiritually/prayers contribute to your emotional well-being in raising your child with Down syndrome? (help to reduce stress)

9. What resources/services/ organizations have helped you better deal with your Down syndrome child?

10. Do you have any comments you feel would be helpful for other parents who are raising a child with Down syndrome to know?

APPENDIX C

INFORMED CONSENT

Informed Consent

The study in which you may voluntarily participate is a study of parental perceptions of coping strategies with children with Down syndrome among Latino and Caucasian cultures. The study is being done by Claudia Campos and Lizbeth Corrales, MSW graduate students at California State University San Bernardino (CSUSB). It has been approved by the Department of Social Work Sub Committee of the California State University of San Bernardino Institutional Review Board.

In this study you first will fill out a survey and then you will participate in an a face-to-face or phone interview. The first part asks questions about your family's characteristics. The second part contains open-ended questions regarding coping with parental stress. The instrument and information you give will not have your name on it to ensure complete anonymity of responses. The interview will be recorded with your permission. Please note that you are not required to fill out the instrument and can refuse to complete the interview at any time you wish. Completion of the interview should take no more then 30 minutes.

Please be assured that findings will be reported in group form only. No information will be used which can identify you. At the conclusion of the study a copy of the findings will be provided to your participating support group.

Questions related to stress as a result of your child with Down syndrome may cause you emotional discomfort. The attached debriefing statement has the name and number of agencies you may contact to help discuss and resolve that emotional discomfort.

If you have any questions or concerns about the study or questions about research participant rights you may contact Dr. Janet Chang, our Faculty Supervisor at (909) 537-5184.

By checking the box provided below and dating this form, you acknowledge that you have been informed, understand the nature of the study, and freely consent to participate. You further acknowledge that you are 18 years of age or over.

I agree to have the interview recorded.

Yes____ No ___

I agree to Participate in the Study

_______ (Check if you agree).

Today's Date is: __________

Forma de Consentimiento

El estudio en el que usted puede participar voluntariamente es un estudio de percepciones paternales de enfrentar las estrategias con niños con el síndrome de Down entre culturas latinas, Negras y Caucásicas. El estudio es hecho por Claudia Campos y Corrales de Lizbeth, estudiantes de posgrado de MSW en Universidad Pública de California San Bernardino (CSUSB). Ha sido aprobado por el Departamento de la asistencia social Sub el Comité de la Universidad Pública de California de San Bernardino la Tabla Institucional de la Revisión.

En este estudio usted llenará primero una inspección y entonces usted tomará parte en una entrevista. La primera parte hace preguntas acerca de sus características de la familia. La segunda parte contiene las preguntas abiertas con respecto a enfrentar con el énfasis paternal. El instrumento y la información que usted da no tendrán su nombre en lo asegurar anonimato completo de respuestas. La entrevista será registrada con su permiso. Por favor nota que usted no es requerido a llenar el instrumento y puede negarse a completar la entrevista en tiempo que usted desea. La terminación de la entrevista no debe tomar más entonces 30 minutos.

Es asegurado por favor que conclusiones serán informadas en la forma del grupo sólo. Ninguna información será utilizada que le puede identificar. En la conclusión del estudio una copia de las conclusiones será proporcionada a su grupo del apoyo que participa.

Las preguntas relacionaron para enfatizar a consecuencia de su niño con el síndrome de Down le puede causar molestia emocional. El interrogatorio conectado la declaración tiene el nombre y el número de las agencias que usted puede contactar para ayudar a discutir y resolverse esa molestia emocional.

Si usted tiene cualquier pregunta o concierne acerca del estudio o preguntas acerca de los derechos de participante de investigación usted puede contactar Dr. Janet Chang, nuestro Supervisor de la Facultad en (909) 537-5184.

Verificando la caja proporcionó debajo de y fechando esta forma, usted reconoce que usted ha sido informado, entienda la naturaleza del estudio, y libremente consentimiento para participar. Usted reconoce aún más que usted es 18 años de la edad o sobre.

Concuerdo en tener la entrevista registrada Sí____ no ___
Concuerdo en Tomar parte en el Estudio _______ (Cheque si usted concuerda).
La Fecha de hoy es: _____________

APPENDIX D

DEBRIEFING STATEMENT

Debriefing Statement

This research study was being conducted by Claudia Campos and Lizbeth Corrales, MSW graduate students at California State University San Bernardino (CSUSB) to find out parental perceptions of coping strategies with children with Down syndrome among Latino and Caucasian cultures. The instrument used in the study is a demographic questionnaire and personal interviews.

If any of the questions asked on the interview or any aspect of the research caused your any emotional stress, you want to discuss the issues further or contact your local family service agency such as, Pomona Valley Hospital at (909) 620-6633. You can find the number of the agency in the yellow pages of your telephone book.

If you have any questions or concerns about the study, you may contact Dr. Janet Chang, our Faculty Supervisor at (909) 537-5184. Also, results of the research project will be available in the Pfau Library at the California State University, San Bernardino by October, 2008 and you can also find it at your local support group.

Declaración del Estudio

Este estudio de investigación fue realizado por Claudia Campos y Lizbeth Corrales, estudiantes de postgrado MSW en Universidad Publica de California San Bernardino (CSUSB). El estudio va a averiguar las percepciones paternales con niños con el síndrome de Down y las estrategias entre culturas Latina y Caucásicas. El instrumento utilizado en el estudio es un cuestionario demográfico y entrevistas personales.

Si cualquiera de las preguntas en la entrevista o cualquier aspecto de la investigación causo cualquier énfasis emocional, o usted quiere discutir los asuntos aun mas, usted puede contactar su agencia local del servicio de la familia como Pomona Valley Hospital en el numero (909) 620-6663. Usted puede encontrar un numero de su agencia local en las paginas amarillas de su guía telefónica.

Si usted tiene cualquier pregunta acerca del estudio, usted contactar Dr. Janet Chang, nuestra Supervisora de la Facultad en el numero (909) 537-5184. También, los resultados del proyecto de investigación estarán disponibles en la Biblioteca de Pfau en la Universidad Publica de California, San Bernardino (CSUSB), en Octubre, 2008 y usted también lo puede encontrar en su grupo local de apoyo.

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ASSIGNED RESPONSIBILITIES PAGE

This was a two-person project where authors collaborated throughout. However, for each phase of the project, certain authors took primary responsibility. These responsibilities were assigned in the manner listed below.

1. Data Collection:

   Assigned Leader: Claudia Campos

   Assisted By: Lizbeth Corrales

2. Data Entry and Analysis:

   Team Effort: Claudia Campos & Lizbeth Corrales

3. Writing Report and Presentation of Findings:

   a. Introduction and Literature

      Team Effort: Claudia Campos & Lizbeth Corrales

   b. Methods

      Team Effort: Claudia Campos & Lizbeth Corrales

   c. Results

      Team Effort: Claudia Campos & Lizbeth Corrales

   d. Discussion

      Team Effort: Claudia Campos & Lizbeth Corrales