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Alicia Gomes

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A COMPARISON OF THE EFFECTS OF PARENTAL STRESSORS IN PARENTS OF DIAGNOSED VERSUS UNDIAGNOSED CHILDREN

by

Alicia Gomes

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Accepted by:

Crystal R. Hill-Chapman, Director of Thesis

Victoria A. Vincent, Reader

Carolyn Lovell, Reader

James Buggy, Dean of The Graduate School

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ABSTRACT

Previous literature has shown that stress can play a major role in family functioning and can be pronounced in families of children with special needs. The purpose of this study is to analyze potential stressors in families of children with special needs to determine whether a diagnosis for a child's medical conditions has any impact on these stressors. Diagnosed and undiagnosed participants were obtained from the National Down Syndrome Society (NDSS), the National Down Syndrome Congress (NDSC), and the Syndromes Without A Name (SWAN) online discussion boards. Participants were solicited with an e-mail providing a link to an online survey with questions assessing their child's diagnosis status, parent's perceived severity of their child's medical conditions, parental stress, reproductive decision-making, marital satisfaction, parental alliance, diagnosis values, demographics, and social support use. A volunteer qualitative interview was done to allow participants to elaborate on areas addressed in the survey. In all, there were 52 participants in the online survey and 15 participants for the volunteer interview. Parental stress values indicate that the undiagnosed population has a statistically significant higher amount of parental stress compared to the diagnosed population (t (39) = 2.282, p = .052). The parent's perception of the child's medical severity also significantly correlates with higher stress levels. It was found that social support significantly predicted parenting stress (p = .002) and explained a statistically significant proportion of variance in parenting stress scores, p = .003. Overall, the results show that both groups found having a diagnosis had more benefits than not having a diagnosis. Ease in receiving therapies and prognosis were most commonly reported as benefits for having a diagnosis within both groups. There were no statistically significant correlations with reproductive decision-making, parental alliance, and marital satisfaction. The results of this study highlight the importance of identifying stressors in families of children with special needs.

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CHAPTER I. BACKGROUND

1.1 Special Needs

Most children in the United States are healthy, requiring little medical management or few medical services except for common childhood illness, injuries, and preventative office visits. However, approximately 1 in 10 children in the United States has a chronic health condition that requires frequent medical care (Turner, 1998). Chronic illnesses in children can range from mild to severe. Despite severity, chronic illness can have effects on other family members that play the role of caretaker for these children. Illness demands can include symptom and treatment monitoring, caretaking, maintaining the family, and ensuring financial stability. Thus, parents must cope with not only the burden of daily care related to illness but also must adjust to changing demands of the illness (Rodenburg, Meijer, Dekovic, & Aldenkamp, 2007; Krulik et al., 1999). While various authors describe a child's medical condition by a number of names, for the purpose of this study, "special needs" will refer to any chronic medical condition that requires additional attention not required for a typically developing child.

1.2 The Special Needs Child in the Family System

Many couples anticipate the joy and excitement that comes with the birth of a new child. While the birth of a new baby is usually a happy occasion in a couple's life, this change in family structure requires new roles to be learned, new relationships developed, and existing relationships realigned (Cowan & Cowan, 1995). As these adjustments are integrated into the pre-existing family system, a child who has special needs can make the process a greater challenge faced by new parents (Damato, 1992). Further increasing the challenge is the adjustments needed in the practical aspects of family life. For example, daily finances must be adjusted in order to accommodate another family member. Additional stress may accompany these financial lifestyle changes (Nyström, 2004). The diagnosis of a birth defect or chronic medical condition would increase the demands on the family's resources. Studies by Turner (1998) have shown that chronic medical conditions can cause varying degrees of added psychological, social, and financial stress on the other members of the family.

A child who has special needs will have their own variations in typical child development. In addition to the health concerns, the changes necessary for family functioning can influence the child's development, growth, academic achievement, social, and psychological function (Turner, 1998). For example, a child may be delayed in development and may walk and talk at a later stage in life. The developmental delays can be more physically demanding for the caretaking parent who must carry the child or perform other duties for their child such as dressing, feeding, etc. In some cases, the delays can be frustrating for both the child and parent, as the child cannot adequately express their needs and wants due to these delays. Within the same example, the family of a child who walks and talks at a later stage in life may be psychologically frustrated and socially isolated because their child cannot associate with other children of the same age. These families may also experience financial strain due to the need for various therapies, additional medical care, and possibly assistive technologies.

Caretaking in itself can be onerous role on a family as it may influence other important aspects of their lives. Studies by Krulik et al. (1999) have found that caring for a child with chronic illness affects the parent's work schedule and adds anxiety when determining important versus unimportant symptoms in their child. Turner (1998) describes caretaking as burdensome for the family as a parent may miss an advancement opportunity in his or her career due to the time necessary for taking care of the child. In addition, a family member may have to give up his or her desired career in order to stay home and become a full time caretaker for the child, as it may easier to stay home with the child than coordinate childcare.

The degree to which a family is able to cope with the special demands of their child depends greatly on factors that reflect family's perspectives of the disability. These perspectives can then influence the family's response to disability from preconception through adulthood (Banks, 2003). Thus, a family's ability to cope with special needs involves many factors surrounding the family. For example, a family's management style, financial status, parental alliance, marital satisfaction, and previous experiences are just a few of the factors affected. The degree to which these areas are impacted depends on the makeup of the family and can provide understanding into their perspectives on disability.

Knalf, Breitmayer, Gallo, & Zoeller (1996) described five types of family management styles that directly influences the way a family will adjust to disability. Each management style involves differences in how the family reflects upon the illness experience, the goals of the family, and how they approach them. Especially important for the family is their view of the consequences of the illness. A *thriving family* tries to maintain a sense of normalcy by trying to minimize the role of illness in the family. These families tend to be overly confident in their parenting and proactive in managing the child's needs. An *accommodating family* is similar to a thriving family but is slightly less confident in their parenting. An *enduring family* puts more of an emphasis on the illness and is more protective and less confident in their parenting. A *struggling family* is less predictable but the mother tends to carry a degree of burden regarding the child's illness and the family is less able to maintain a degree of normalcy. A *floundering family* is most concerning as they put major emphasis on the illness and is unable to cope (Knalf et al., 1996). Family management styles are important because they provide understanding of how a family will be affected by special needs. As a result, a family with a special needs child functioning in a thriving style is better able to achieve a sense of normalcy than a family who maintain a floundering style. Management styles are important in identifying which families will be most negatively impacted by the addition of a child who has special needs.

In addition to family management styles, other factors can determine how a family is able to cope with a child who has special needs. Population-level data by Mistry and colleagues have shown that rearing a young child who has special needs requires considerable social, financial, and health care resources (Mistry, Stevens, Sareen, Vogli, & Halfon, 2007). When a child has special needs, medical bills begin to surge as frequent medical and hospital visits, costly medications, services and therapies become necessary. As a result, if a family is not financially stable, this may require family members to take on undesired roles working inside or outside the home (Sen & Yurtsever, 2007). Furthermore, when resources such as finances are scarce, psychological distress is seen in these families. Dellve, Samuelsson, Tallborn, Fasth, and Hallberg (2005) note that special needs can negatively influence a family of low socioeconomic status and when social support is absent, mental health problems such as depression and anxiety are seen in other members of the family.

1.3 Role of Knowledge on a Family

Knowledge of the child's special needs can also play a major role in determining how a family will cope. Some of the problems associated with families who lack knowledge about their child's condition include feeling isolated with the problem, difficulty in obtaining a correct diagnosis or finding information about the disease, and managing daily care (Dellve et al., 2005). With limited knowledge of etiology, parents must make complex decisions about the meaning of symptoms and the symptom's implications for their children (Krulik et al., 1999). Studies have shown that any family who has a child who has special needs may feel some level of responsibility or guilt for their child's conditions (Sen & Yurtsever, 2007). Krulik et al. (1999) also described the extreme guilt parents experience when they misinterpret symptoms and the criticism from health care professionals for bringing a child to the hospital too quickly or too late. Families without a diagnosis who are still in search of knowledge of the etiology may face the stress of numerous physician and specialist's evaluations while still experiencing grief that their child is not the typically developing child they initially hoped for (Chomicki & Wilgosh, 1992).

When thinking about the effects of a child's special needs on the parents, it is important to consider what factors influence family dynamics. One of these factors is if there is a diagnosis for the child's difficulties. One percent of all newborns have multiple congenital anomalies and in the majority of these children, there is no etiological explanation for the child's condition (Lenhard, Breitenbach, Ebert, Schindelhauer-

Deutscher, & Henn, 2005). Multiple diagnostic procedures and therapies may be performed with limited success, which increases the family's financial burden and psychological distress.

Uncertainty causes frustration as families continue to go to various doctors in search of a diagnosis (Sen & Yurtsever, 2007). As a result, this may cause dysfunction within the family system as the parents expend a great deal of physical and emotional energy searching for an etiology or diagnosis. Katz & Lazcano-Ponce (2008) summarized the effects of *not* having a diagnosis by stating:

> *The impossibility of attaining the expected goals generates a great deal of frustration and can lead to serious errors in child rearing, which without doubt, significantly affects the psychological development of these children. As a result, parents must face the correct diagnosis to minimize the denial mechanism (S135).*

The work of Lenhard et al. (2005) indicated that the parents of children with multiple congenital anomalies of an unknown cause reported that a diagnosis would have an impact on labels, causes, prognosis, treatment, acceptance, and social support. When it comes to their child's prognosis, the parents wanted to know about future threats to their child's health or life, and were looking for a realistic estimation about the developmental boundaries and goals for their child. Thus, parents without a diagnosis have many questions and concerns that only a definitive diagnosis could answer.

The degree of certainty of the diagnosis also can be used to predict emotional strain, feelings of guilt, and anxiety in mothers of children with different forms of disability. Bourke et al. (2008) discovered that having a diagnosis was associated with positive maternal health and psychological well-being. In fact, those parents with a definite diagnosis for their children, like Down syndrome, tend to cope with the situation more easily in comparison to those parents of children without a clear etiology (Lenhard et al., 2005). Also, with Down syndrome, there is a greater tendency for the affected child to gain acceptance from both the parents and society, which causes less to be demanded of them (Hodapp, 2007).

Roach, Orsmond, and Barratt (1999) studied families with a known diagnosis and discovered that children with Down syndrome were easier to parent than children with other disabilities but more difficult to parent than typically developing children. This study also highlights that a parent's involvement in childcare also serves as a predictor of parental stress. For example, a mother's parenting stress was positively associated with children's caregiving complications; a father's parenting stress was negatively associated with his child's labelling, such as typically developing versus Down syndrome. This is an excellent example of how having a diagnosis can decrease stress levels and family dysfunction, and increase parenting function.

Not having a diagnosis can also influence reproductive decisions of other family members and siblings of a child who has special needs. Without a diagnosis, the recurrence risk for having another child who has special needs is unknown. Decisions about future family planning in reproduction can be uncertain for both parents and siblings (Lenhard et al., 2005). Research by Ahmed et al. (2008) has shown that many families make termination decisions based on their perception of suffering endured by the child. This suffering can be physical (e.g., medical treatments) or emotional (e.g., psychological or social factors). Ahmed et al. concluded that it is ideal for families to have as much information as possible about their child’s illness before making reproductive decisions. With this information, family members will be more confident in making reproductive decisions.

1.4 Special Needs and Parents

Parents of children who have special needs place higher expectations on themselves that affects experienced stress, well-being, and ways of coping (Dellve et al., 2005). With the additional demands of daily treatment and increased daily housework, parents of children who have special needs can be limited in their family’s social contacts and may feel that the child’s special needs dominate family life (Nuutila & Salanter, 2006). The family’s ability to cope with their child’s special needs can be determined by studying the expectations of the parents on the family and each other. These expectations can be further examined by asking questions that pertain to the parent’s well-being, marital satisfaction, parental alliance, and parental stress.

1.5 Parental Well-being

Care giving is defined as a primary role of parents and is required by a family member in order to take care of a special needs child. This becomes a concern when the time and efforts needed for care giving affects the physical health and mental happiness or well-being of the parent. When it comes to parental well-being, mothers seem to be more negatively affected than fathers are. In one study, mothers tended to feel severe sadness after having a child who has special needs. These mothers also reported that their social and work lives were affected along with their other family relationships (Sen & Yurtsever, 2007). Further research indicated that these mothers were shown to be at an increased risk for stress, poorer health and weakened family relationships (McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008). In addition, Lenhard et al. (2005) have shown that disability, uncertainty, hope, and emotion-centered coping were significant risk factors for a parent's emotional well-being.

The parents are not only responsible for well-being of their child who has special needs, but for the entire family. They are also responsible for making changes and seeing that the needed structural and functional alterations promote long-term health for all family members (Krulik, 1999). The way parents react and treat their children who have special needs has a direct impact on the long-term psychological well-being of these at-risk children. Furthermore, parents of children who have special needs, especially mothers, run an increased risk of having personal poor health and lack of overall well-being that is mostly related to psychological strain (Dellve et al., 2005).

1.6 Stress

It is not surprising that families dealing with children who have special needs have higher levels of stress than families who do not have children who have special needs (Rodenburg, 2007). Many common stressors have been seen in families dealing with special needs. One stressor is perception of the child's behavior and how it contributes to stress in parent-child interactions. Studies have shown that a child with a more difficult temperament is a source of stress for parents (Rodenburg, 2007). Other stressors affecting parents include parental perception of the severity of the illness, frequency of hospitalization, financial stability, and availability of social support. Distress can also be related to the perception of whether the child looks different when compared to other children (Krulik, 1999). Parental stress can be used as a determinant of dysfunctional parenting, or parenting that has negative impacts for both parent and child (Rodenburg R, 2007).

1.7 Marital Satisfaction and Parental Alliance

The level of well-being and happiness of the parents appears to influence their parenting behavior directly. Marital conflict is a negative indicator for poor emotional health in the marriage partners and their children (Whitson & El-Sheikh, 2003). Stress can be an underlying factor that can affect these relationships as parents try to respond to the increased demands of caretaking a child who has special needs that diverts time and attention that would have been given to adult relations (Turner, 1998).

Marital stress includes three dimensions that determine the level of stress within the relationship. The three dimensions are the ways each partner is affected by the stressful event, the origin of the stress and whether it comes from inside or outside the couple, and the length of time that the stressor exists (Randall & Bodenmann, 2009). In general, the parents' needs are summarized in three main themes: the need for "normality and certainty," the need for information, and the need for partnership (Dellve et al., 2005). The marital relationship can be a major social support for parents. Satisfaction in the marital relationship can be equally assumed to relieve parenting stress and, in turn, to positively affect parenting (Rodenburg, 2007). Alternatively, if there is disatisfaction in the marital relationship, this can be a primary stress factor that undermines parenting function.

1.8 Use of Social Support Systems

Stress, however, does not affect all families in the same manner. In general, potential buffers for determining stress levels include child characteristics (age, sex, behavior), disability characteristics (burden of disease), caregiver characteristics (age, marital status and satisfaction, coping style), family characteristics (functioning, resources), sociological characteristics (social support, employment, socio-economic status) and system characteristics (family-centered care) (Bourke et al., 2008). According to Bourke et al., of the potential buffers mentioned, social supports seem to be one of the most important. When a tight knit social network is present in a family or community, a positive association has been seen between the parent's ease, competence, and verbal/emotional responsiveness (Webster-Stratton, 1990). Social supports can provide both positive and negative influences on families dealing with special needs. Support can come in many forms but it is important that the support helps to influence the well-being and empowerment of the parents.

1.9 Rationale and Purpose

In summary, stress can affect any family with the introduction of a new child, as new roles must be learned, new relationships developed, and existing relationships realigned (Cowan & Cowan 1995). When the child has any special need, this stress is compounded, but it can be alleviated through knowledge of their child's disease, prognosis, treatment, and care. In addition, in some families, the child may have multiple medical conditions but no known underlying cause for why these conditions are happening to their child. When a family does not know the etiology, these facets are unclear. Without a diagnosis, parents are also uncertain about the recurrence risk for their child's special needs that can have an effect on future family planning. For the parents, having a child who has special needs can have direct effects not only on their own levels of stress, but also on their personal well-being and overall marital satisfaction.

Parents of children who have special needs have a decrease in both physical and mental health (McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008). High amounts of stress can also cause marital dissatisfaction that may affect divorce decisions and family dynamics. (Dellve et al., 2005).

Little research focuses on the undiagnosed population although they make up the majority of patients that enter a pediatric genetics office. There have been studies that have measured stress levels in isolation, such as research conducted by Krulik et al. (1999), but these studies have not used comparisons based on illness etiology and knowledge. On the other hand, studies such as those conducted by Bourke et al. (2008) have looked into the stress and well-being of parents for specific syndromes such as Down syndrome. Others have stated that within the Down syndrome community, lower amounts of stress and divorce rates have been seen when compared to other multiple anomaly disorders (Roach and Orsmond, 1999). No one has taken a complete look at the same stressors focused on in this research: stress levels, financial status, martial satisfaction, parental alliance, and future family planning.

This study is designed to compare levels and causes of stress in families who have a child who has special needs to families with a diagnosis for their child's special needs. The purpose of this study is to determine whether the stress levels may be different based on whether there is a known diagnosis. This study is important to the special needs community in order to understand better what struggles a family may be dealing with outside of the medical issues presented in clinic. With this information, proper referrals can be made and issues can be addressed to ease the effects of the illness and provide support not only for the child, but also for the entire family.

This study will compare stress levels in both populations of parents with a known versus unknown diagnosis for their special needs child to see if there is a correlation with marital satisfaction and reproductive decision-making. There are four hypotheses.

1. The lack of information in not having a diagnosis will produce an increased amount of stress in this population when compared to a diagnosed population.
2. The increase in parental stress in the undiagnosed population will negatively correlate with marital satisfaction and parental alliance and use of social supports.
3. The diagnosed and undiagnosed populations will differ in what they believe a diagnosis will do for them.
4. Those without a diagnosis for their child will choose not to have more children more frequently than those with a diagnosis for their child.

By measuring stress, marital satisfaction, future family planning, and social supports, these aspects that surround family functioning can be measured in order to determine the role of disability etiology in the big scheme of family life.

CHAPTER II: MANUSCRIPT

A COMPARISON OF THE EFFECTS OF PARENTAL STRESSORS IN PARENTS OF DIAGNOSED VERSUS UNDIAGNOSED CHILDREN[1]

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2.1 Abstract

Previous literature has shown that stress can play a major role in family functioning and can be pronounced in families of children with special needs. The purpose of this study is to analyze potential stressors in families of children with special needs to determine whether a diagnosis for a child's medical conditions has any impact on these stressors. Diagnosed and undiagnosed participants were obtained from the National Down Syndrome Society (NDSS), the National Down Syndrome Congress (NDSC), and the Syndromes Without A Name (SWAN) online discussion boards. Participants were solicited with an e-mail providing a link to an online survey with questions assessing their child's diagnosis status, parent's perceived severity of their child's medical conditions, parental stress, reproductive decision-making, marital satisfaction, parental alliance, diagnosis values, demographics, and social support use. A volunteer qualitative interview was done to allow participants to elaborate on areas addressed in the survey. In all, there were 52 participants in the online survey (23 diagnosed, 24 undiagnosed). Five families were unsure of their child's diagnosis status and were omitted from analysis. There were 15 participants for the interview (5 diagnosed, 10 undiagnosed). Parental stress values indicate that the undiagnosed population has a statistically significant higher amount of parental stress compared to the diagnosed population (t (39) = 2.282, *p* = .052). The parent's perception of the child's medical severity also significantly correlates with higher stress levels. It was found that social support significantly predicted parenting stress (*p* = .002) and explained a statistically significant proportion of variance in parenting stress scores, *p* = .003. Overall, the results show that both groups found

having a diagnosis had more benefits than not having a diagnosis. Ease in receiving therapies and prognosis were most commonly reported as benefits for having a diagnosis within both groups. There were no statistically significant correlations with reproductive decision-making, parental alliance, and marital satisfaction. The results of this study highlight the importance of identifying stressors in families of children with special needs.

2.2 Introduction

Approximately 1 in 10 children in the United States has a chronic health condition that requires frequent medical care (Turner, 1998). Illness demands on the parents can include symptom and treatment monitoring, caretaking, maintaining the family, and ensuring financial stability that forces parents to cope with the burden of daily care related to illness and adjustment to changing demands of the condition (Rodenburg et al., 2007; Krulik et al., 1999). A study by Turner (1998) has shown that such medical conditions can cause varying degrees of added psychological, social, and financial stress on the other members of the family.

A child who has special needs will have his/her own variations in typical child development. In addition to the health concerns, these changes can affect the child’s development, growth, academic achievement, social, and psychological function (Turner, 1998). The developmental delays can be more physically demanding for the caretaking parent who must physically carry the child or perform more duties for their child such as dressing, feeding, etc. The delays can be frustrating for both the child and parent, as the child cannot adequately express their needs and wants due to these delays. Caretaking in itself can have an important but burdensome role on a family. Studies by Krulik et al.

(1999) have found that caring for a child with chronic illness affects the parent's work schedule and adds anxiety when determining important versus unimportant symptoms in their child.

The degree to which a family is able to cope with the special demands of their child depends greatly on factors that reflect family's perspectives of the disability. These perspectives can then influence the family's response to disability from preconception through adulthood (Banks, 2003). A family's management style, financial status, parental alliance, marital satisfaction, and previous experiences may also influence the family's ability to cope with the disability. The degree to which these areas are impacted depends on the makeup of the family and can provide understanding into their perspectives on disability.

One important practical factor that can affect coping is financial status. When a child has special needs, medical bills begin to surge as frequent medical and hospital visits, costly medications, services and therapies are necessary. As a result, if a family is not financially stable, this may require family members to take on undesired roles working inside or outside the home (Sen & Yurtsever, 2007). Examples can be seen in research by Dellve et al. as they note that special needs can negatively affect a family of low socioeconomic status.

Knowledge of the child's special needs can also play a major role in determining how a family will cope. Some of the problems associated with families who lack knowledge about their child's condition include feeling isolated with the problem, difficulty in obtaining a correct diagnosis or finding information about the disease, and managing day-to-day care-giving (Dellve et al., 2005). Studies have shown that any family who has a child who has special needs may feel some level of responsibility or guilt for their child's conditions (Sen & Yurtsever, 2007). Families without a diagnosis who are still in search of knowledge of the etiology may face the stress of numerous physician and specialist evaluations while still coming to terms with the internal concerns that their child is not the typically developing child they initially hoped for (Chomicki & Wilgosh, 1992).

One percent of all newborns have multiple congenital anomalies, and the majority of these children have no etiological explanation for the child's condition (Lenhard et al., 2005). Uncertainty causes frustration in the parents as they continue to go from various doctor to doctor in search of a diagnosis (Sen & Yurtsever, 2007). Lenhard et al.'s work (2005) indicated that the parents of children with multiple congenital anomalies of an unknown cause reported that a diagnosis would have an impact on labels, causes, prognosis, treatment, acceptance, and social support. When it comes to their child's prognosis, the parents wanted to know about future threats to their child's health or life, and were looking for a realistic estimation about the developmental boundaries and goals for their child.

The degree of certainty of the diagnosis can also be used to predict emotional strain, feelings of guilt, and anxiety in mothers of children with different forms of disability. Bourke (2008) discovered that having a diagnosis was associated with positive maternal health and psychological well-being. In fact, those with a definite diagnosis, like Down syndrome, tend to cope with the situation more easily when compared to those parents of children without a clear etiology (Lenhard et al., 2005).

Not having a diagnosis can also affect reproductive decisions of other family members and siblings of a child who has special needs. Without a diagnosis, the recurrence risk for having another child who has special needs is unknown. Research by Ahmed et al. (2008) has shown that many families make termination decisions based on their perception of suffering endured by the child. This suffering can be physical (e.g., medical treatments) or emotional (e.g., psychological or social factors). Ahmed et al. concluded that it is ideal for families to have as much information as possible about their child's illness before making reproductive decisions. With this information, family members will be more confident in making reproductive decisions.

Parents of children who have special needs place higher expectations on themselves and each other, which influence experienced stress, well-being, and ways of coping (Dellve et al., 2005). With the additional demands of daily treatment and increased daily housework, parents of children with special need can be limited in their family's social contacts, and may feel that the child's special needs dominate the lives of the whole family (Nuutila & Salanter, 2006). One can determine how well a family will cope with disability by studying the expectations of the parents on the family and each other. These expectations can be determined by closely studying the dynamics of the parent's well-being, marital satisfaction, and parental alliance and affect of stress levels on both the mother and father.

Care giving is defined as a primary role of parents and is required by a family member in order to take care of a special needs child. This becomes a concern when the time and efforts needed for care giving affects the physical health and mental happiness or well-being of the parent. When it comes to parental well-being, mothers seem to be more negatively affected than fathers are. Research indicated that these mothers were shown to be at an increased risk for stress, poorer health and weakened family relationships (McConkey, Truesdale-Kennedy, Chang, Jarrah, & Shukri, 2008). In addition, Lenhard et al. (2005) have shown that disability, uncertainty, hope, and emotion-centered coping were significant risk factors for a parent's emotional well-being.

It is not surprising that families dealing with children who have special needs have higher levels of stress than families who do not have children who have special needs (Rodenburg, 2007). Many common stressors have been seen in families dealing with special needs. One stressor is perception of the child's behavior and how it contributes to stress in parent-child interactions. Other stressors affecting parents include parental perception of the severity of the illness, frequency of hospitalization, financial stability, and availability of social support. Distress can also be related to the perception of whether the child looks different when compared to other children (Krulik, 1999). Parental stress can be used as a determinant of dysfunctional parenting, or parenting that has negative impacts for both parent and child (Rodenburg, 2007).

The level of well-being and happiness of the parents appears to influence their parenting behavior directly. Marital conflict is a negative indicator for poor emotional health in the marriage partners and their children (Whitson & El-Sheikh, 2003). Studies have shown that the increased demands of caretaking a child who has special needs that diverts time and attention that would have been given to adult relations and therefore can affect parental relationships (Turner, 1998).

Marital stress includes three dimensions that determine the level of stress within the relationship. The marital relationship can be a major social support for parents. Satisfaction in the marital relationship can be equally assumed to relieve parenting stress and, in turn, to positively affect parenting (Rodenburg, 2007). Alternatively, if there is disatisfaction in the marital relationship, this can be a primary stress factor that undermines parenting function.

Stress, however, does not affect all families in the same manner. In general, potential buffers for determining stress levels include child characteristics (age, sex, behavior), disability characteristics (burden of disease), caregiver characteristics (age, marital status and satisfaction, coping style), family characteristics (functioning, resources), sociological characteristics (social support, employment, socio-economic status) and system characteristics (family-centered care) (Bourke, 2008). According to Bourke, of the potential buffers mentioned, social supports seem to be one of the most important. When a tight knit social network is present in a family or community, a positive association has been seen between the parent’s ease, competence, and verbal/emotional responsiveness (Webster-Stratton, 1990). Social supports can provide both positive and negative influences on families dealing with special needs. Support can come in many forms of which, an important area can be support for the well-being and empowerment of the parents.

Little research focuses on the undiagnosed population although they make up the majority of patients that enter a pediatric genetics office. There have been studies that have measured stress levels in isolation, such as research conducted by Krulik et al. (1999), but these studies have not used comparisons based on illness etiology and knowledge. On the other hand, studies such as those conducted by Bourke et al. (2008) have looked into the stress and well-being of parents for specific syndromes such as Down syndrome. No one has taken a comprehensive look at the stressors focused on in the research: stress levels, martial satisfaction, parental alliance, and future family planning.

This study was designed to compare levels and causes of stress in families who have a child who has special needs to families with and without a diagnosis for their child's special needs. The purpose of this study was to determine whether the stress levels may be different based on whether or not there was a known diagnosis. There were four hypotheses. The first hypothesis was that not having a diagnosis will produce an increased amount of stress in this population when compared to a population that has a diagnosis. The second was that the increase in parental stress in the undiagnosed population will negatively correlate with marital satisfaction and parental alliance and use of social supports. Third, the diagnosed and undiagnosed populations would differ in what they believe is the value in having a diagnosis. Lastly, those without a diagnosis for their child would choose not to have more children more frequently than those with a diagnosis for their child.

These aspects that surround family functioning were measured in order to determine the role of disability etiology in the big scheme of family life. This study may be important to the special needs community in order to understand better what struggles a family may be dealing with outside of the medical issues presented in clinic. With this information, proper referrals can be made and issues can be addressed to ease the effects of the illness and provide support not only for the child, but also for the entire family.

2.3 Methods

2.3.1 Participants

The participants were parents/caregivers of children who have special needs between the ages of 3-10 with and without a known diagnosis of their child. The undiagnosed group was recruited from the national support group Syndromes without a Name (S.W.A.N.). S.W.A.N. has approximately 300 families who have children with multiple congenital anomalies that have no underlying etiology. For the diagnosed population, the Down syndrome support groups National Down Syndrome Society (NDSS) and National Down Syndrome Congress (NDSC) were used to recruit participants.

2.3.2 Apparatus

This survey was designed to examine if there is a diagnosis for a family's child who has special needs, the disease severity, child prognosis, parental stress levels, marital satisfaction, parental alliance, and reproductive decisions. The survey was created using both questions written by the researcher as well as standardized questionnaires such as the *Parenting Stress Index –Short Form* (Abidin, 1995), the *DAS-7* (2001), the *Parental Alliance Index* (Abidin, 1995) and the *Multidimensional Scale of Perceived Social Support* (Zimet, Dahlem, Zimet & Farley, 1988). Please see Appendix 2 for all questions asked within the survey.

Disease Severity, Diagnosis, and Reproductive Decision Making. Original questions were developed to look at opinions on having a diagnosis, disease severity, and reproductive decision-making.

Parenting Stress Levels. The *Parenting Stress Index-Short Form* (Abidin, 1995) was used to examine levels of parenting stress. It is comprised of 36 questions. This scale measures parental distress as a subscale by measuring distress in the parenting role. The Parental Stress Index-Short Form also measures dysfunctional interaction through a subscale that measures the parent's perception of their relationship with their child to determine if they believe the relationship is reinforcing. This scale previously shown high internal consistency and has good test-retest reliability. For this study, internal consistency reliabilities were 0.91 for the total stress scale, 0.90 for the parental distress subscale, 0.91 for the parent-child dysfunctional interaction subscale, and 0.71 for the difficult child subscale. Scoring for this scale was based upon pre-established cutoff points where scores of 36 or more were considered high for parent distress while a score of at least 27 on the parent-child dysfunctional scale were considered high.

Marital Satisfaction. For marital satisfaction, the *DAS-7* (Hunsley, Best, Lefebvre, & Vito, 2001), a shortened form of the Spanier's Dyadic Adjustment Scale, was used. It is comprised of seven questions. This scale can be used to determine if a marriage is classified as distressed or adjusted. The scale uses a Likert-type scale and has good internal consistency. For this study, the internal consistency reliability was 0.89.

Parental Alliance. For parental alliance, the *Parental Alliance Index* (Abidin, 1995) with 20 questions was used. This scale can be used to determine what degree parents believe that both parents have a cohesive relationship in parenting. This scale has good internal consistency. For this study, the consistency reliability was 0.97.

Social Support. To determine if the individual completing the survey had adequate social support, the *Multidimensional Scale of Perceived Social Support* (Zimet, Dahlem, Zimet & Farley, 1988) with 20 questions was used. Demographic questions have also been asked in order to determine characteristics of the participants and to determine who will continue the survey and complete the marital components. This scale has been shown to have adequate internal consistency. For this population, the consistency reliability was 0.94.

A qualitative interview was also performed with those who volunteered while completing the survey. The participants were asked a series of questions written by the researcher. See Appendix 3.

2.3.3 Design.

A letter was sent to each support group's discussion board that explained the purpose of this study. Please see Appendix 1for a copy of the letter. The letter provided an online address to Survey Monkey where the survey was located. The survey took approximately 20-25 minutes to complete and those that accessed the survey had the option to exit the survey at any time. At the end of the survey, participants had an opportunity to indicate if they were interested in participating in a qualitative interview. While information can be obtained through survey use, qualitative telephone interviews were conducted to ensure that the parents have the opportunity to provide as much detail about their stressors and family dynamics as they are willing to share.

2.3.4 Analysis.

In order to interpret these results, survey tools that have been published and standardized were used to measure parental stress levels, marital satisfactions levels, and parental alliance levels. To determine if the diagnosed and undiagnosed population's perceptions differed in what they believe a diagnosis will do for them, an analysis of frequencies was completed. To determine if the lack of information in not having a diagnosis will produce an increased amount of stress in this population when compared to a diagnosed population, a t-test was performed. Next, to determine if increase in parental stress was negatively correlated with marital satisfaction, parental alliance, and use of social supports, a linear regression was performed. Finally, for the hypothesis that those without a diagnosis for their child will choose not to have more children more frequently than those with a diagnosis for their child, a chi square test, and analysis of frequencies were performed.

SPSS (Version 18.0) was used to run the univariate and multivariate statistical tests to compare parental stress levels, marital satisfaction levels and parental alliance levels. We have also used these values to compare against responses to demographic, disease severity, and reproductive decision making questions that have been written.

Qualitative questions have been transcribed and analyzed for any underlying themes within responses.

2.4 Results

2.4.1 Demographics.

Demographic information was obtained from the survey participants in the following areas: relationship to the child, age, race, marriage status, education level, household income, number of children, age of child, and diagnosis information. Of the participants, 95% (44) were mothers, 2% (1) was a father, and 2 % (1) had another relationship to the child. The ages of the participants were widely distributed (see Figure 1). However, the racial background was 98% Caucasian and 2% Asian/Pacific Islander. Marital status was broken down as follows: 95% were married, 2% were separated, 4% were divorced, and 2% were in a long-term relationship. Participants predominantly had at least a college education (see Figure 2) and the average income for those individuals who had a diagnosis for their children was approximately $81,900. The average income for those who were undiagnosed was $71,764, but there was no statistically significant difference between these means (*p* = .99). Most participants had three children, and 96% have only one child who has special needs (see Figure 3). The overall average age of the children who have special needs was 4 years, 4 months old for the diagnosed group and 5 years, 3 months old for the undiagnosed group. There were no statistically significant differences in demographics between the diagnosed and undiagnosed groups.

Figure 2.1. Age of Participants

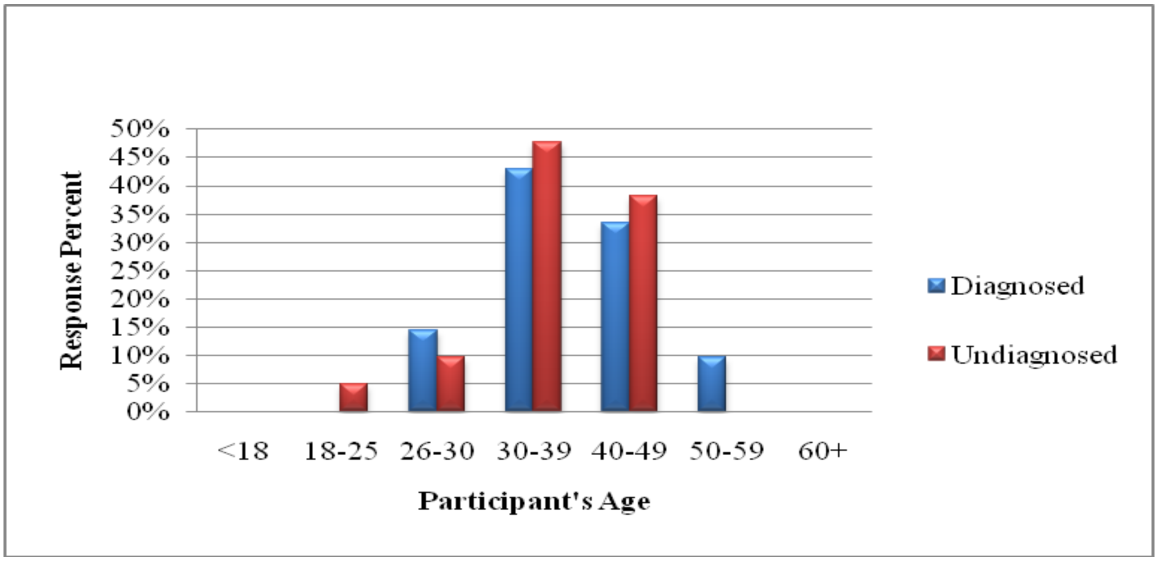


Figure 2.2. Participants' Highest Educational Level Completed

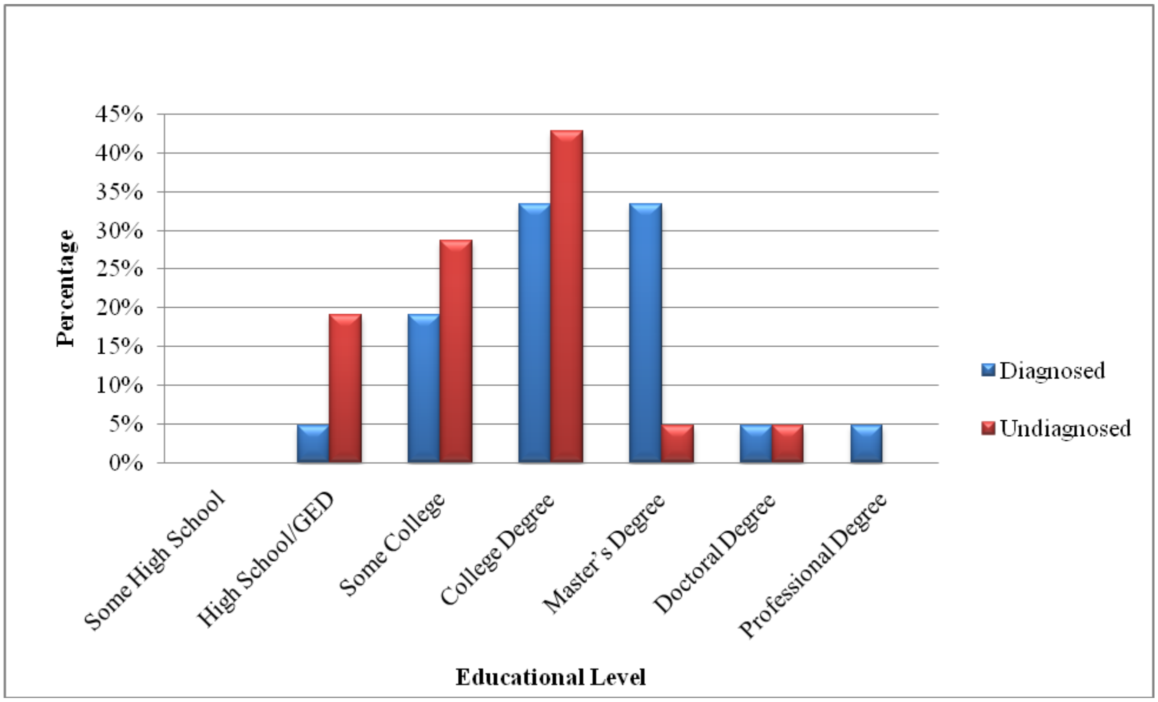
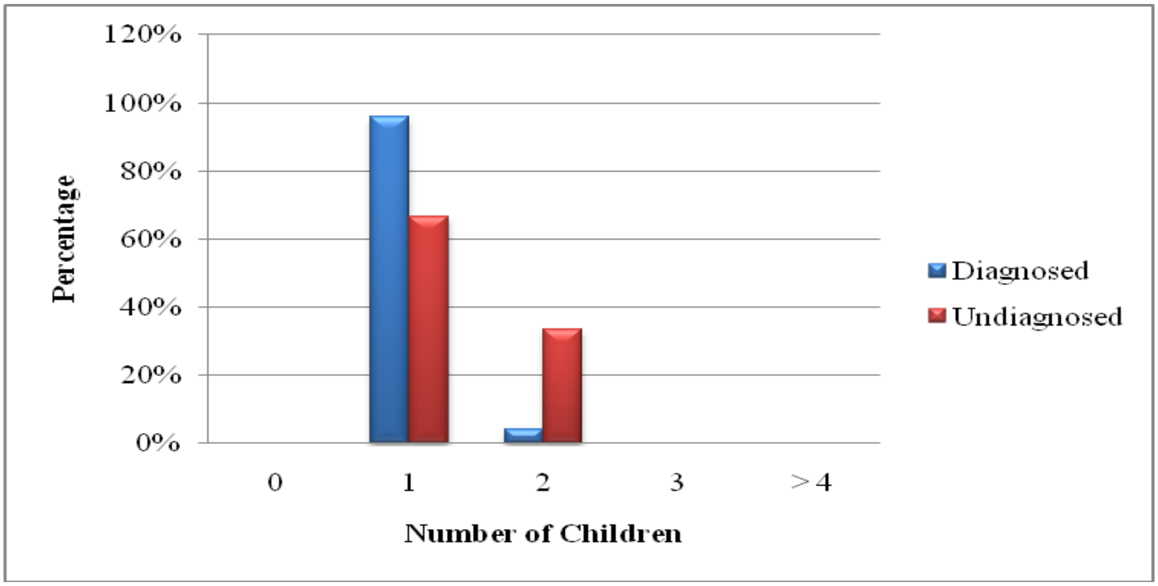


Figure 2.3. Number of Children with Special Needs



2.4.2 Description of study subjects.

Of the 52 children represented by this survey, 23 had a diagnosis while 24 did not, and five families were unsure whether their child had a diagnosis. For analysis purposes, the unsure participants were omitted. For the qualitative interviews, 15 participants were interviewed, five had a diagnosis and 10 did not. The parents of children with a diagnosis received a diagnosis by birth while those without a diagnosis have been searching since their child was less than 1 year old. The average number of medical problems reported for these children was three for both the diagnosed group and undiagnosed group, with feeding problems being reported as the most severe medical condition. The most common medical conditions for each group were feeding and muscle conditions for the diagnosed while feeding and intellectual impairment were most common for the undiagnosed. Figures 4a and 4b summarize the medical conditions reported most often by the parents for their children. There was no statistical difference in the severity of overall health reported between the diagnosed and undiagnosed populations. Figure 5 represents the therapies used by the two groups studied. The most commonly used services for both groups were occupational therapy and physical therapy, while the undiagnosed group also tended to use financial assistance more than the diagnosed group.

Figure 2.4a. Major Medical Conditions Most Reported by Parents of Children with Diagnosed Disorders

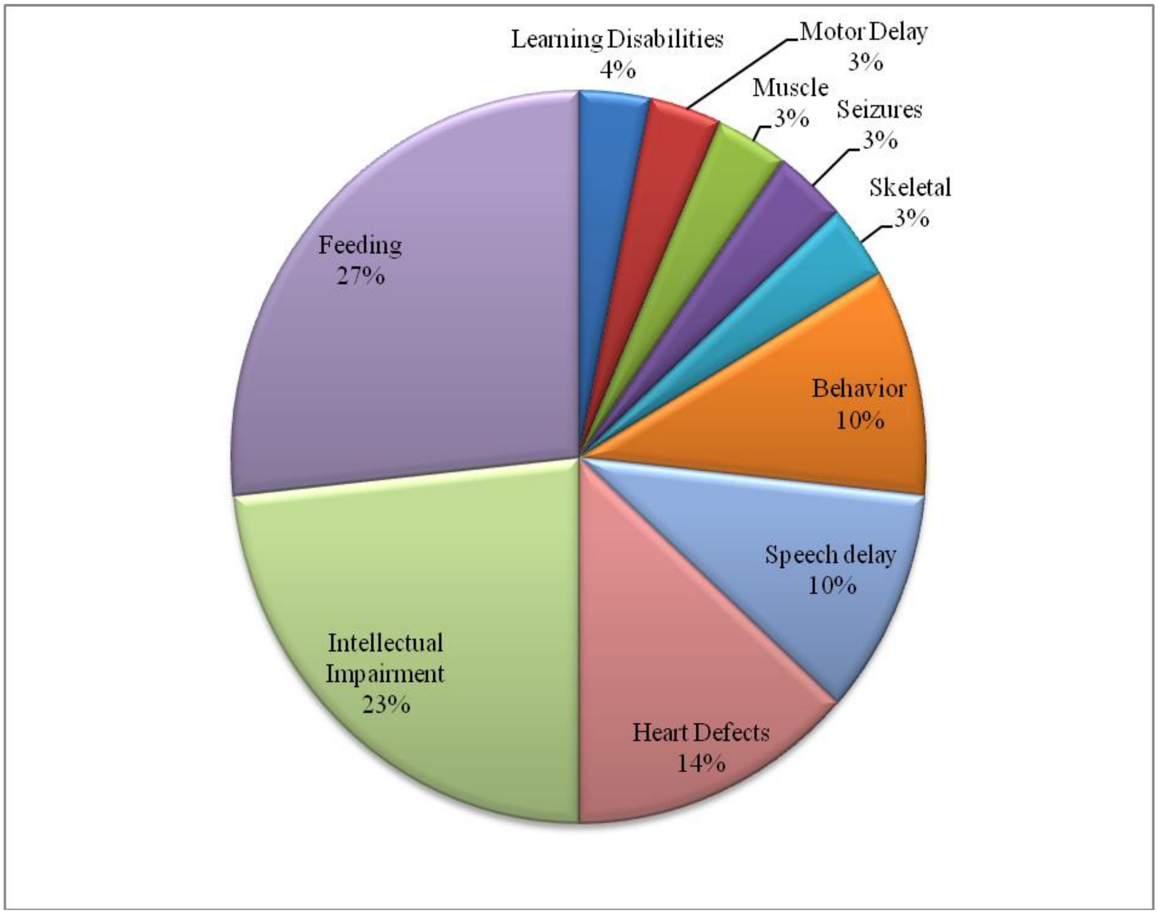


Figure 2.4b. Major Medical Conditions Most Reported by Parents of Children with Undiagnosed Disorders

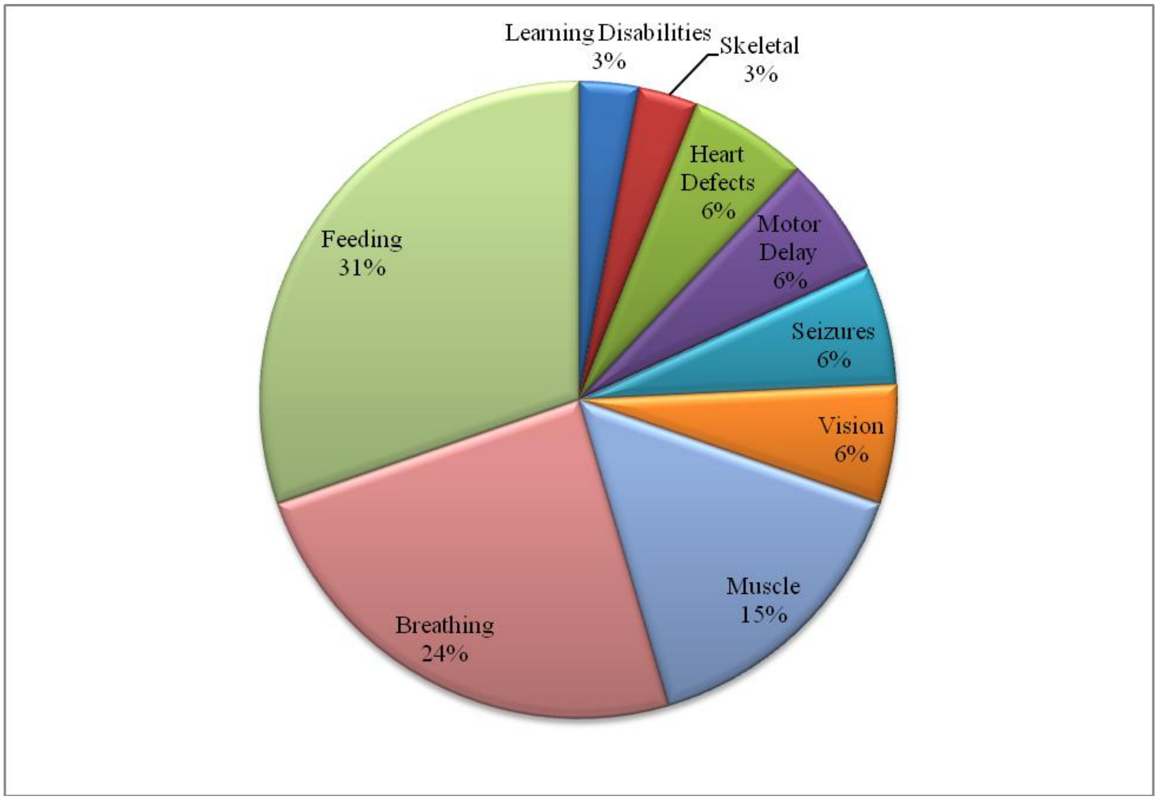
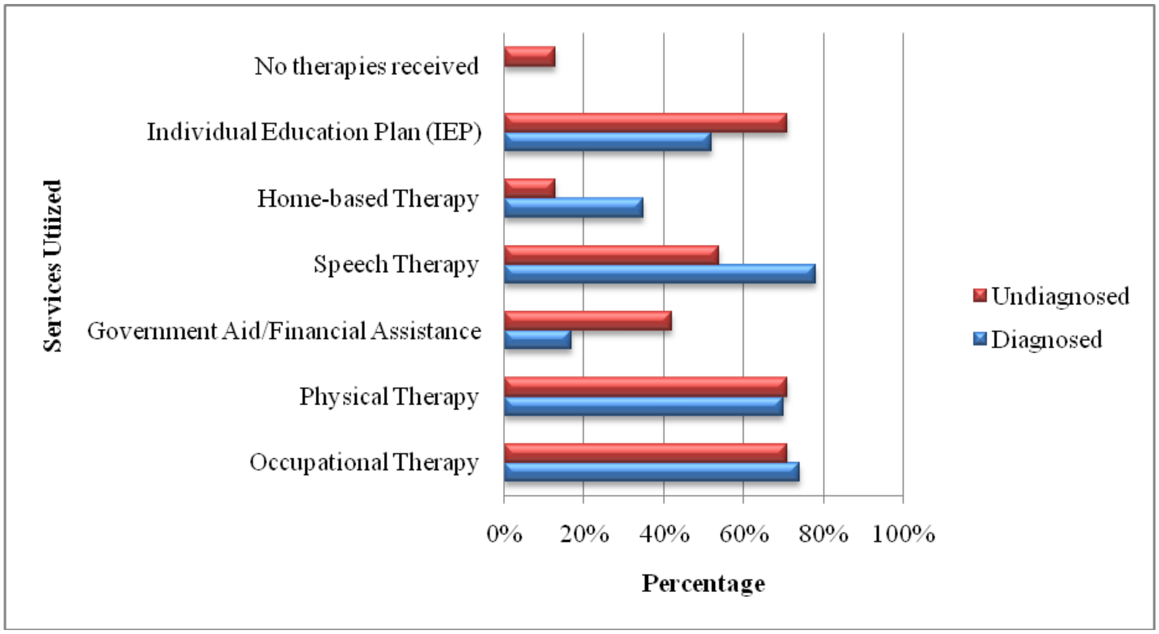


Figure 2.5. Services Utilized by Each Group



2.4.3 Parental Stress

In this study, analysis was performed to determine any correlations between parental stress and the diagnosed and undiagnosed populations. Through a comparison of means, it was found that both groups reported high amounts of parental stress ($M = 130.5$, $SD = 26.02$ diagnosed; $M = 115$ undiagnosed, $SD = 16.68$). A t-test of total parental stress values indicates that the undiagnosed population has a statistically significant higher amount of parental stress as compared to the diagnosed population (t (39) = 2.28, $p = .052$).

A common theme uncovered during analysis of interviews was the stress involved in managing their child's care, routine household chores, and balancing the care for multiple children. Finances were also commonly reported as a source of stress.

> *My shoes are always running kids everywhere. I try to keep the house clean with little kids everywhere. I try to get bills done, food, and getting the kids everywhere.*
>
> *We have to feed her every 3-4 hours and sometimes she fights or pulls the feeding tube out. Finances should be an issue, but I don't worry about it. I live from paycheck to paycheck, but I think everybody does.*
>
> *I do stretches with my son and I put him on the bus and drive my other son to school. Depending on what school calls me first, I go to doctor's appointments. Probably in a month, we go to 8-10 doctors' appointments. The number of people that we juggle, one of my sons has 18 teachers. There is so much going on. I get shut off notices. I don't know if I'm coming or going. Everybody wants you to practice something*

> *at home, and this is between two kids and we are working. I can't find the difference between being my child's doctor and being my child's parent. You want them to do everything, but it's a challenge because you want them to come home and relax.*
>
> *I had to go get help myself because I was getting depressed. I had to quit my job because [my daughter] is a full time job. We don't have any friends; we can't get out. My husband and I can't go out to eat alone. Financially we lost my salary, I was a nurse making good money and we don't have that and my husband's job keeps him out of town.*

Two of the 15 interviewees reported depression and others reported the need for personal time for maintaining their well-being. Many reported the value in respite care and other forms of child monitoring that allowed them free time to do other things.

> *My son gets PCA hours, personal care attendant hours. He has them but I use them mainly for work. I use them for pampering myself. Sometimes I go grocery shopping, but I don't usually use them for me time.*
>
> *I never get time for myself. I rarely, maybe 2-3 times a month meet my sister and we get our nails done or maybe meet a friend for drinks. There is no time.*
>
> *Taking time out for myself is the hardest thing in the world. That's hard for any mom. I read for fun.*
>
> *Not that often. Mainly because I have 4 children and my oldest is nine. Even working out I have to have someone take care of the younger*

> *ones. Respite care has been very helpful. My daughter says the lady takes her swimming and they go out to eat.*

2.4.4 Marital Satisfaction, Parental Alliance, and Social Support

The last hypothesis was that the increase in parental stress would negatively correlate with marital satisfaction, parental alliance, and use of social supports. A measure of both marital satisfaction and parental alliance using the *DAS-7* and *Parental Alliance Index* showed that there was no statistically significant difference between the diagnosed and undiagnosed populations [χ^2 (72, n = 45) = 72.32, *p* = .47]. Both populations had high levels of marital satisfaction and parental alliance. For marital satisfaction, a comparison of means showed a mean of 21.48 and standard deviation of 6.82 for the undiagnosed and a mean of 20.85 and a standard deviation of 7.77 for the diagnosed population (for both groups *M* = 21.13, *SD* = 6.91). When analyzing marital satisfaction, a mean of 48.15 and a standard deviation of 9.33 was found for the undiagnosed population and a mean of 51.40 and standard deviation of 9.89 for the diagnosed population (collectively *M* = 49.67, *SD* =9.21). In addition, a linear regression of marital satisfaction, parental alliance, and social support showed no statistically significant impact on parental stress for parental alliance and marital satisfaction. However, a linear regression did show that social support statistically significantly predicted parenting stress scores (r^2 = .47, *t* (39) = 3.40, *p* = .002). Social support also explained a statistically significant proportion of variance in parenting stress scores (r^2 = .312, *F* (3, 39) = 5.44, *p* = .003).

Common themes when analyzing the interviewee’s responses were that the mother was the primary caregiver. Nearly 50% of those interviewed reported using some form of outside help when dealing with differences within the marriage. In addition, many families stressed how important communication and talking was when discussing disagreements within the marriage.

> *We have not seen a marriage counselor. We are involved in a church. They are a good support cause they are there when we need to talk about it. We really don't have a whole lot of differences but when we do, we talk it out.*
>
> *We didn't get any counseling, but we go to church together and sponsor engaged couples. This has brought us closer together.*
>
> *We discuss. We are good talkers. He's very logical and I yell.*
>
> *We can't be the priority right now. He couldn't wake up form one of his surgeries. It's more important than who did the dishes today. The things we would normally fight about we just don't have that.*

Use and need for support groups was also a common theme among those interviewed.

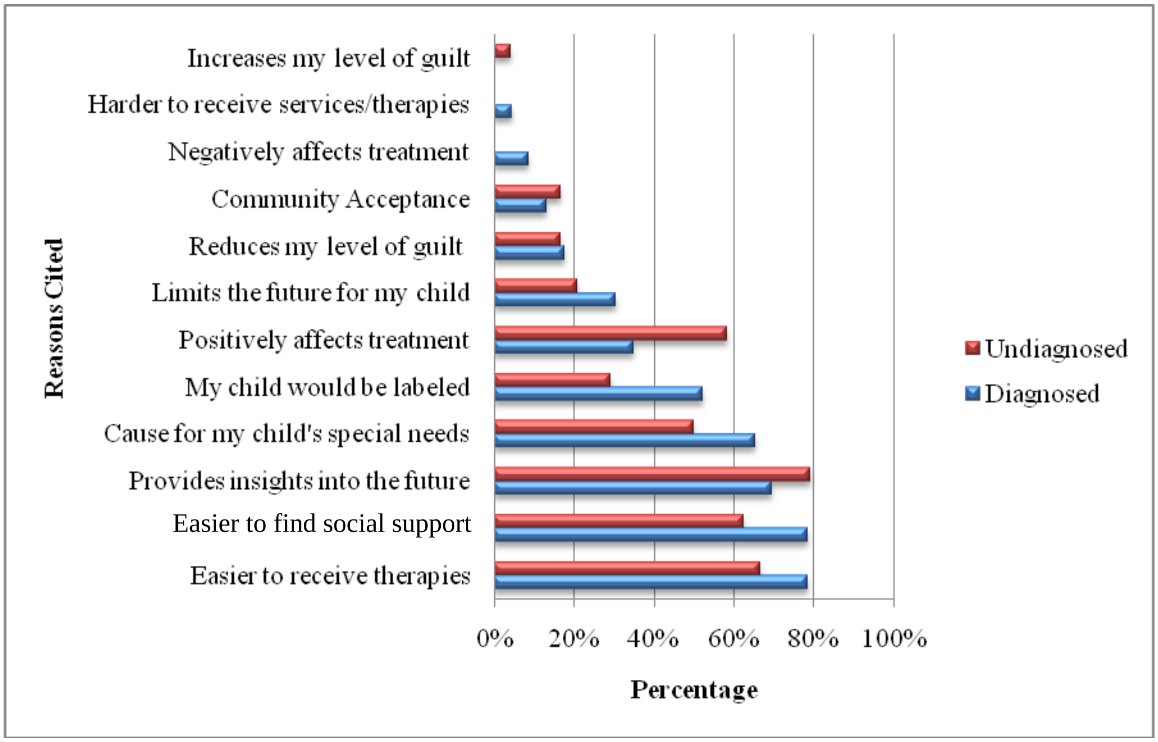
> *We have to find people who are equipped to take care of both of them. We don't have a lot of family. When I ask them why you don't spend more time with my kids, it's because they are a little more special.*
>
> *I mostly use internet groups of people with similar conditions or technologies. I get some help from extended family, but its more them helping with my other kids.*
>
> *I have friends that I met on line that have either cranio or heart conditions and have gone across the country to meet. We talk constantly on the internet. We've known each other for 9 years.*

> *We have a family in our church, she had a child with a rare chromosome disorder, and I know I can call on her for support. I wish there was ways to find more families out there. But really it's just the Down syndrome out there and that doesn't relate to me.*

2.4.5 Value of a Diagnosis.

This study also compared the populations to determine their values in a diagnosis. Both groups report that having diagnosis had more benefits than not having a diagnosis. Of the possible benefits in having a diagnosis, ease in receiving therapies and insight into the future were most commonly reported as benefits for having a diagnosis in both groups. These frequencies have been reported in Figure 6. Of note, 34.8% of the diagnosed population found ease in receiving treatment for medical conditions as a benefit of having a diagnosis, while 58.3% of the undiagnosed found this as a benefit. In the diagnosed population, 78.3% found ease in finding social and emotional supports as a benefit while 62.5% of the undiagnosed agreed. When looking at community acceptance, 13% of the diagnosed and 16.7% of the undiagnosed groups found acceptance of the community as a benefit of having a diagnosis.

Figure 2.6. Value of a Diagnosis



Upon review of the responses from the families who were interviewed, no one found a benefit in not having a diagnosis. Another common theme was that a diagnosis would provide a roadmap to their child's future, as many stated that a not having a diagnosis provided a lot of worry in the unknown.

> *In her case it's really about helping to make decisions on what treatments to pursue and which not to pursue. It's more about palliative care now. We make decisions with her comfort in mind. We don't do anything invasive. If we had a diagnosis, and a given treatment, this would have a profound impact on our choices.*
>
> *Not knowing the prognosis and not knowing what to expect. Seeing a constant decline and not knowing what is going to come next. It is difficult to plan for her future. It would depend on what the diagnosis*

> *is, if I was told it was terminal that would be hard to handle but [the shock] would be short term.*
>
> *With a diagnosis, you have the validation that you are doing everything that you can be doing. If something happen, God forbid, if they found something on an autopsy and we could have done something about it, that would be the worst fear. Doctors are not always right so you are constantly asking yourself; did you push hard enough? Did I convey what I'm trying to say hard enough? Do they think I'm just overwhelmed?*
>
> *The discouragement you feel when you want a diagnosis, and you get one, but you don't get answers. You want this; this is what you should look for when she goes to a doctor. You wish for a roadmap, but it's not there.*

Upon review of the negative implications of a diagnosis, the most common theme was an impact on labeling. Those with and without a diagnosis feel that a diagnosis influences how their child would be labeled by the community, both positively and negatively.

> *I understand that having the diagnosis kicked in the services to be preventive. But now, everything about his life falls under that umbrella. Without a diagnosis, you will allow them to develop at their own pace. Sometimes I feel like you want them not to get off the track you are always pushing them on.*
>
> *It gave us a name, but it didn't give us a lot of information. It's broad stuff they say for any chromosome disorder. [A diagnosis] gives*

> *you a name and hope that there is some information out there. And, before the diagnosis, they were always talking about her and you are always fighting for your child.*
>
> *When people ask me what's wrong, I can't give a name to describe it. If she had Down syndrome, I could say that, and they could understand what she has. And then what comes along with that is that people ask a lot of questions and I don't mind that but it gets tiring repeating things over and over again.*
>
> *To explain better to other people what's wrong with her. People say, 'Wow she's small. Why?' Most times its words they don't understand so they just glaze over. It is most difficult to explain it in social circles, such as church. You can tell she's different but you can't put your finger on it. We always say she has dwarfism.....what's dwarfism?*

2.4.6 Reproductive Decision Making.

Analysis was performed to compare our diagnosed and undiagnosed populations based upon their reproductive decisions. A chi-square analysis indicated that the proportion of parents in the diagnosed group who planned to have more children after having a child who has special needs was 0.04, whereas the proportion from the undiagnosed group was .083. However, the difference in proportions was not statistically significant, χ^2 (4, N = 52) = 9.06, *p* = .06.

The most common reason for the diagnosed population to decide not to have more children was that they have reached their ideal family size. A chi-square analysis of this factor was found to be statistically significant, χ^2 (2, n = 23) = 6.37, *p* = .041. Although not found to be statistically significant, the most common reason for the undiagnosed population was that they needed too much time to take care of their child, χ^2 (2, n = 24) = 3.55, *p* = .170.

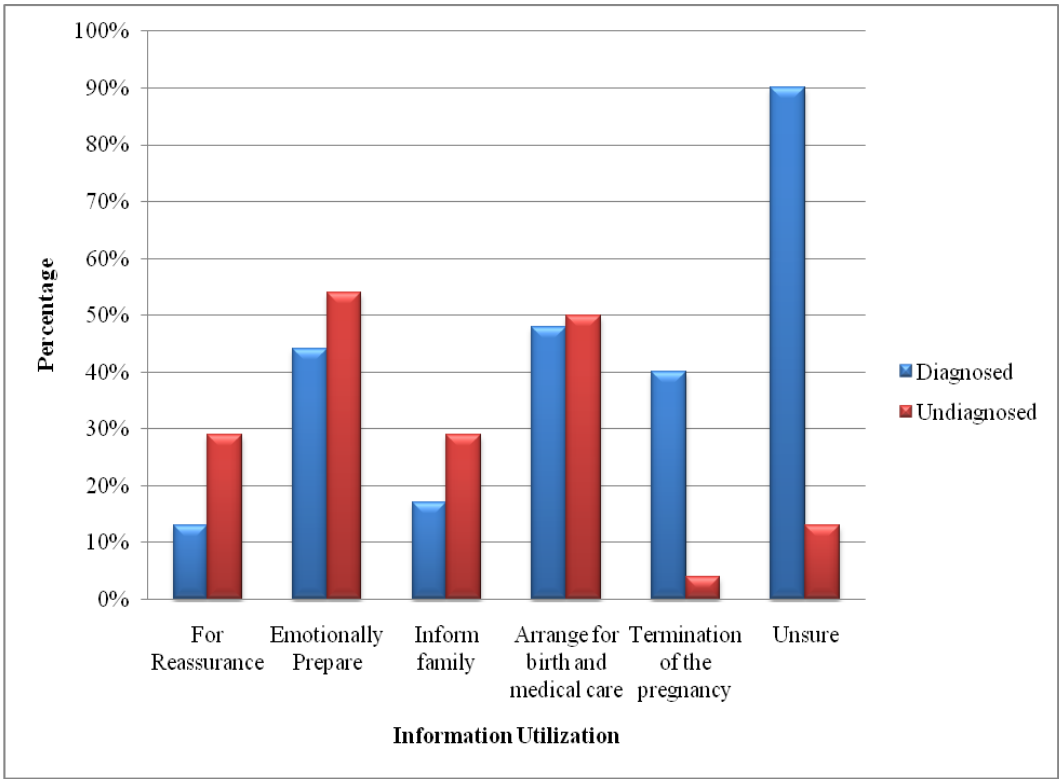
Many of the families interviewed reported common themes involving the excessive amount of time necessary to take care of a child who has special needs, as well as the risk they may be taking if the diagnosis is genetic.

> *I did go through a phase after he was born where I had to have another baby to show that I can have a typically developing kid. But he had two [normally] developing kids and he didn't need any more but I got over it. I don't know if it's because Paul is doing so well or if I've just accepted it.*
>
> *We have to plan everything around her. Even a trip to the grocery store has to be orchestrated. I think things would be different if she wasn't in our lives. But we have both chosen career paths that we necessarily wouldn't if she hadn't been there in our lives.*
>
> *He was my last. I was 32 when I had him, I was already done. If I was younger I still would have had more kids; he is what he is.*
>
> *It makes me fearful of having another child. I think it's the fear of having another child with a disability and the time…I want my son to have more.*

> *She was the last one, but now for sure she is the last one. Because of the time for care and the fear of having another child like that, even though the odds are slim.*

Approximately half of parents (52% of the diagnosed group and 58% of the undiagnosed group) would choose prenatal diagnosis to determine if their next child had the same condition as their affected child. Figure 7 summarizes what each group would decide to do with this information. The most common use for testing by both groups was reassurance and birth/medical arrangements.

Figure 2.7. Utility of Prenatal Diagnostic Information



A comparison of the proportions of parents in the diagnosed group who felt they were at-risk for having another child who has special needs was .42, whereas the proportion from the undiagnosed group was .17. However, the difference in proportions was not statistically significant, χ^2 (4, N = 47) = 4.74, *p* = .315.

2.5 Discussion

In medicine, one goal is to determine the cause and treatment of a patient's presenting symptoms. In genetics, a similar goal is to determine the underlying cause of a person's medical conditions and possibly identify and predict potential issues that may affect medical management. As a result, when a family presents to pediatric genetics, the parents expect that a cause will be discovered. While detection rates on many tests ordered may not be very high, as technologies and knowledge improves in genetics, more and more etiologies may be found (Ledbetter & Faucett, 2008). Given such hope, many families search for diagnoses for their children for years (Chomicki & Wilgosh, 1992). The question then becomes, "What is the value of having a diagnosis?"

In this study, parental stress and other family stressors such as marital satisfaction, parental alliance, and social support were compared in families with and without a diagnosis for their child's special needs. We have learned that many families continue to search for a diagnosis with the hope that a diagnosis will provide a roadmap for their child's future, while others hope for a treatment or service that will improve their child's health. The issue that many undiagnosed families may not realize is that as new genetic testing technologies improve and diagnostic power increases for different conditions, the practical application of the diagnosis in terms of treatment or prediction of the clinical course often lags behind. A diagnosis may not mean any major changes in medical management. Although a diagnosis may not change medical management, it is important to determine if or how a diagnosis could affect a family in other ways. A study by Lenhardt (2005) has shown that a diagnosis could affect cause, prognosis, treatment, acceptance, and social support for the family. Thus, diagnosis may also affect parental stress and family functioning.

One hypothesis was that the lack of information in not having a diagnosis would produce an increased amount of stress in the undiagnosed population when compared to a diagnosed population. While parental stress can be found in any family structure, this stress is generally higher when the family has a child who has special needs (Rodenburg, 2007). In this study, a statistically significant difference was found as those without a diagnosis scored higher amounts of stress than those with a diagnosis. This increase in stress may be due to the fear related to not knowing. As many parents state the desire for a roadmap to their child's medical issues, it is easy to see how the fear from not knowing may cause additional stress as they frequent doctor's offices, sift through a number of diagnoses, and learn the variety of possible future implications.

When analyzing interviews of the participants, undiagnosed groups found that the numerous doctor appointments and the not knowing in general was a common source of stress. As seen in previous literature (Lenhard et al., 2005), families represented in this study also believe a diagnosis will reduce the stress that multiple doctors' visits can cause on a family. Families believe that with a diagnosis, the stress related to these visits will be alleviated. While the child may have, fewer tests performed and less doctor's visits strictly for diagnosis discovery, many families may not realize that any visits for a specific medical condition will continue at the same frequency, with or without a diagnosis. A diagnosis may not decrease these visits.

Upon further analysis using spearman's rho, it was also determined that a statistically significant correlation was found between parent's perception of theseverity of a child's medical conditions and parental stress [ρ (2, N=45) =.001 p =.477]. There was no correlation between severity and diagnosis. While diagnosis status may be important, it is as important to understand that parent's perception of the child's severity in order to find ways to ease stress levels. While medical professions cannot simply create a diagnosis when one is unknown, severity perception is a stressor that can be impacted through dialogue and necessary referrals in order to decrease parental stress.

This study also compared parental stress with marital satisfaction, parental alliance, and use of social supports. There was no statistically significant association between parental stress and marital satisfaction or parental alliance and parental stress. However, parental stress and social support were found to be significantly correlated. In this study, parents with higher amounts of parental stress reported less social support. In fact, the linear regression analysis showed that the parental stress was negatively correlated with social support and especially so in those without a diagnosis. During interviews with parents, many participants reported that while they felt they had support from various family members and friends, many expressed the value of having someone to talk with going through the same issues as their family.

One factor that is directly impacted by diagnosis and parental stress is social support. In this study, it was found that social support was a predictor of parental stress. In addition, those with a diagnosis reported a higher amount of social support than those without a diagnosis. It may be important to recognize the role that outside support can play in a family. Perhaps, a parent feels isolated without finding others with the same diagnosis and therefore may not have an outlet source to relieve stress that they feel. While all participants were members of an online support group, there was still a statistically higher amount of social support reported for those with a diagnosis as 78% of the diagnosed and 63% of the undiagnosed groups also report that a diagnosis would increase social support.

Another hypothesis was that the diagnosed and undiagnosed populations would differ in what they value in a diagnosis. While more than three-fourths of those with a diagnosis were more likely to find that a diagnosis benefits through ease in receiving therapies, the undiagnosed population found that a diagnosis was most beneficial for prognosis. Of note, neither group believed that a diagnosis would be beneficial in gaining acceptance into the community or guilt relief for their child's special needs.

Lastly, it was hypothesized that those without a diagnosis for their child will choose not to have more children more frequently than those with a diagnosis for their child. After analysis of the results from this study's participants, there is a statistically significant difference in that those with a diagnosis choose not to have more children more frequently than those without a diagnosis. Recurrence risk and future family planning can also be directly affected by a diagnosis. Although diagnosis can determine recurrence risk, it seems that for the families who participated in this study this is not an important issue. In most cases, these families had already decided that they would not have additional children. Many stated that this was due to the additional time and impact of caring for their affected child.

A common option offered in a genetic counseling session is prenatal testing. While both groups would use this if it were available, the most commonly cited reasons for using this information were to prepare emotionally and to seek medical management as oppose to termination of the pregnancy. While use of testing would not alter future family planning, it is still important to offer prenatal testing when possible in order to help families feel more in control and emotionally prepared to rear a child who has special needs.

From this study, the importance in assessing family dynamics as a whole can be seen as the medical status of the child can directly affect the parents and other family members. It is important for genetic counselors to assess possible parental stressors and offer as much social support a family is willing to accept. As more and more rare diagnoses are made, it may be equally as beneficial simply to find families dealing with similar issues instead of attempting to find families with the same diagnosis.

The results of this study may not represent the population of parents of a child with special needs as a whole due to the characteristics of our participant population.Over 90% of the participants were Caucasian females. Male care providers and those from other ethnic groups were underrepresented in this participant population. Studies by Rodenburg (2007), however, suggest that there is no difference between the stress experienced by mothers and fathers of children who have special needs. The high percentage of female participants could perhaps influence the results on social support, as women are more likely to seek out social support more so than men. This should be taken into consideration when interpreting this information to represent a broader community. In addition, over 90% of the population studied reported high levels of marital satisfaction, which does not reflect marriage statistics reported in previous literature (Doss B, Rhoades G, Stanley S, Markman H, 2009; Neff & Karney, 2009). Marital satisfaction scores may also impact areas of parental stress, financial stress, and reproductive decision making that may be more specific to single or divorced populations. The results may not be the same for those parents who report lower levels of marital satisfaction.

It is important to keep in mind that the participants were members of an online support group with access to a computer system. Those who do not have access to computers due to lower socioeconomic factors or educational levels would not be represented in this study. An online support group can also provide a level of support that those who are not in a support group may not have. While this study found a negative correlation between social support and parental stress, this correlation could be even more profound in a population with no form of social support. In addition, because this population is a part of an online support group, these participants may have a higher underlying need for social support than those with no form of social support.

The participants were recruited through advertisement on the respective support groups' discussion boards. Only those who chose to participate progressed to completing the survey. In addition, interviews were provided on a volunteer basis of those who chose to participate in the initial survey. This sample population may differ from the general population as they may have ulterior motivations making them more inclined to participate in the survey and influence their responses.

Lastly, the primary diagnosis represented in this study is Down syndrome. The parents within the Down syndrome community may not share the same views as parents of children with other diagnoses. In future studies, it would be important to include a more diverse group of diagnoses in order to compare the views of the various communities as they may deal with different types of medical, developmental, and social issues. This information could influence their stress levels and stressors making this study less general to all diagnosed groups.

This study has provided insight into parental stress experienced by caregivers of children with or without having a diagnosis for their child's with special needs. In future studies, it would be important to expand this knowledge into more diverse backgrounds, especially those coming from lower socioeconomic status. Future studies, could also delve deeper into the role of social support in families in order to determine if families seek additional social support due to a void within familial support or perhaps they are better able to receive additional supports due to the satisfaction found within their familial support system.

2.6 Conclusion

In this study, we have compared parental stress and other family stressors such as marital satisfaction, parental alliance, and social support in families from the NDSS, NDSC, and SWAN support groups. These families were separated by those with and without a diagnosis for their child's special needs also in order to learn more information on their perception of a diagnosis. While a diagnosis can be useful for reproductive decision-making and medical management, there are a number of other aspects that a diagnosis can perform for a family. Many families value a diagnosis to provide a possible roadmap into the future for their child.

This study found that those with a diagnosis have lower amounts of parental stress than those without a diagnosis. Some of the parents in the undiagnosed group expressed that this stress came come from the fear related to not knowing. Parents fear not knowing what future conditions can arise in their child and not knowing if they are doing everything possible to provide proper care for their child. Whether a diagnosis changes medical management, at least a family can have reassurance that they are doing everything possible for their child.

This study has found that there is a significant correlation with perceived medical severity and parental stress. A common theme uncovered during analysis of interviews was the stress involved in managing their child's care when it involved multiple treatments and therapies. As this also plays a major factor in parental stress, it is important that perceived severity is addressed and assessed in medical offices in order to help validate or even alleviate the stress that a parent may feel related to their child.

Parental stress and social support were found to be significantly correlated. In this study, parents with higher amounts of parental stress reported less amounts of social support. In addition, those with a diagnosis reported a higher amount of social support than those without a diagnosis. Another valuable lesson that the field of genetic counseling can take from this study is the value of social support for a family. While a family may believe that they have ample support from family members, friends, and their surrounding peers, many still long for the ability to talk with a family who may be going through similar issues. As learned from this study, social support seems to mediate the relationship between diagnosis and parental stress. It is important for health providers to give patients as much access to others dealing with similar complications, with or without a diagnosis. This study has provided insight into parental stress as well as the lives of those without a diagnosis. For future studies, it would be important to expand this knowledge into other backgrounds especially those coming from lower socioeconomic status. Future studies, could also delve deeper into the role of social support in families in order to determine the exact type of support that these families feel that they are lacking.

CHAPTER III. CONCLUSIONS

In this study, we have compared parental stress and other family stressors such as marital satisfaction, parental alliance, and social support in families from the NDSS, NDSC, and SWAN support groups. These families were separated by those with and without a diagnosis for their child's special needs also in order to learn more information on their perception of a diagnosis. While a diagnosis can be useful for reproductive decision-making and medical management, there are a number of other aspects that a diagnosis can perform for a family. Many families value a diagnosis to provide a possible roadmap into the future for their child.

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REFERENCES

Abidin, R. R. (1995). *Parenting Stress Index: Professional Manual* (3rd ed.). Odessa, FL: Psychological Assessment Resources, Inc.

Ahmed, S., Hewison, J., Green, J., Cuckle, H. S., Hirst, J., & Thornton, J. (2008). Decisions About Testing and Termination of Pregnancy for Different Fetal Conditions: A Qualitative Study of European White and Pakistani Mothers of Affected Children. *Journal of Genetic Counseling*, *17*, 560-572.

Banks, M. E. (2003). Disability in the Family: A Life Span Perspective. *Cultural Diversity and Ethnic Minority Psychology*, *9*(4), 367-384.

Bourke, J., Ricciardo, B., Bebbington, A., Aiberti, K., Jacoby, P., Dyke, P., et al. (2008). Physical and Mental Health in Mothers of Children with Down syndrome. *Journal of Pediatrics*, *153*, 320-326.

Chomicki, S., & Wilgosh, L. (1992). Health Care Concerns Among Parents of Children With Mental Retardation. *Children's Health Care*, *21*(4), 206-212.

Cowan, C., & Cowan, P. (1995). Interventions to ease the transition to parenthood: why they are needed and what they can do. *Family Relations*, *44*(4), 412-423.

Damato, M. L. (1992). Parenting and supportive programs, NAACOG's clinical issues in Periantal and Women's Health. *Nursing*, *3*(1), 174-187.

Dellve, L., Samuelsson, L.,Tallborn, A., Fasth, A., Hallberg, L R-M. (2005). Stress and well-being amoung parents of children with rare diseases: a prospective intervention study. *Issues and Innovations in Nursing Practice*, 53(4), 392-402.

Doss, B.D., Rhoades, G.K., Stanley, S.M., Markman, H.J. (2009). The Effect of the Transition to Parenthood on Relationship Quality: An 8-Year Prospective Study. *Journal of Personality and Social Psychology*, *96*(3), 601-619.

Hodapp, M.H. (2007). Families of Persons with Down syndrome: New Perspectives, Findings, and Research and Service Needs. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 279-281.

Hunsley, J., Best, M., Lefebvre, M., & Vito, D. (2001). The seven-item short form of the Dyadic Adjustment Scale: Further evidence for construct validity. *American Journal of Family Therapy, 29*(4), 325-335.

Katz, G., & Lazcano-Ponce, E. (2008). Intellectual disability: definition, etiological factors, classification, diagnosis, treatment and prognosis. *Salud Publica de Mexico, 50*(2), S132-S141.

Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1996). Family Response to Childhood Chronic Illness: Description of Management Styles. *Journal of Pediatric Nursing, 11*(5), 315-326.

Krulik T., Turner-Henson, A., Kanematsu, Y., Al-Ma'aitah, R., Swan, J. & Holaday, B. (1999). Parenting Stress and Mothers of Young Children with Chronic Illness: A Cross-Cultural Study. *Journal of Pediatric Nursing, 14*(2),130-140.

Ledbetter D.H.& Faucett W.A. (2008). Issues in genetic testing for ultra-rare diseases: background and introduction. *Genetic Medicine, 10*(5), 309-313.

Lenhard W, Breitenbach, E., Ebert, H., Schindelhauer-Deutscher, H.J. & Henn, W. (2005). Psychological Benefit of Diagnostic Certainty for Mothers of Children with Disabilities: Lessons From Down syndrome. *American Journal of Medical Genetics Part A, 133*(2), 170-175.

McConkey, R., Truesdale-Kennedy, M., Chang, M.-Y., Jarrah, S., & Shukri, R. (2008). The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultrual study. *International Journal of Nursing Studies, 45*, 65-74.

Mistry, R., Stevens, G. D., Sareen, H., Vogli, R. D., & Halfon, N. (2007). Parenting-Related Stressors and Self-Reported Mental Health of Mothers with Young Children. *American Journal of Public Health, 97*(7), 1261-1268.

Neff, L.A., & Karney, B.R. (2009). Stress and Reactivity to Daily Relationship Experiences: How Stress Hinders Adaptive Processes in Marriage. *Journal of Personality and Social Psychology, 97*(3), 435-450.

Nuutila, L., & Salanter, S. (2006). Children with a Long-Term Illness: Parents' Experiences of Care. *Journal of Pediatric Nursing, 21*(2), 153-160.

Nyström, K., & Öhrling, K. (2004). Parenthood experiences during the child's first year: literature review. *Journal of Advanced Nursing*, 46(3), 319-330.

Randall, A. K., & Bodenmann, G. (2009). The role of stress on close relationships and mariatal satisfaction. *Clinical Psychology Review, 29*, 105-115.

Roach, M. A., Orsmond, G. I., & Barratt, M. S. (1999). Mothers and Fathers of Children with Down syndrome: Parental stress and involvement in childcare. *American Journal on Mental Retardation, 104*(5), 422-436.

Rodenburg, R., Meijer, A. M., Dekovic, M., & Aldenkamp, A. P. (2007). Parents of children with enduring epilepsy: Predictors of parenting stress and parenting. *Epilepsy & Behavior, 11*, 197-207.

Sen, E., & Yurtsever, S. (2007). Difficulties Experienced by Families With Disabled Children. *Journal for Specialists in Pediatric Nursing, 12*(4), 238-252.

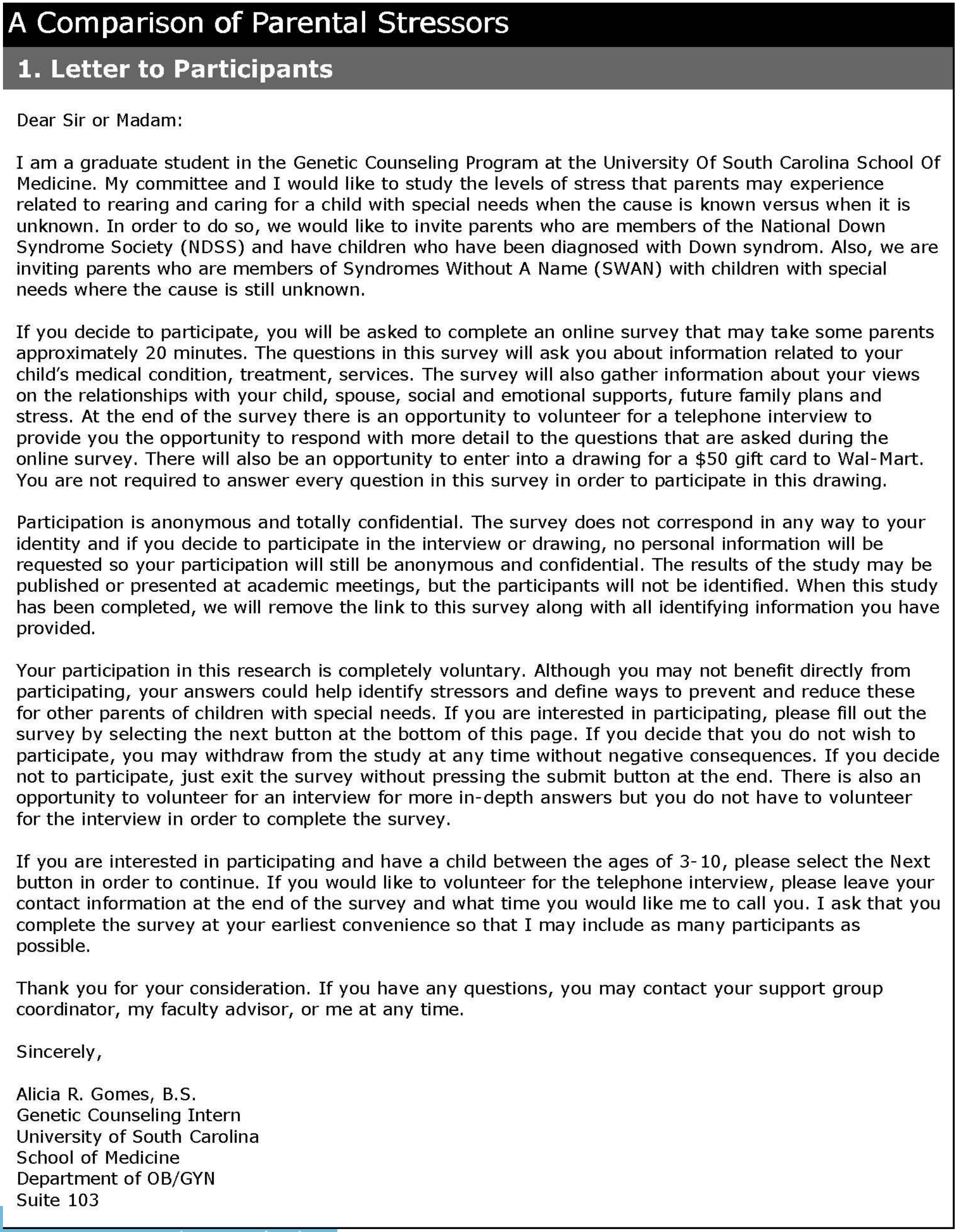
Turner, J. L. (1998). Children with Chronic Illness. *Medical Update for Psychiatrists, 3*(2), 45-48.

Webster-Stratton, C. (1990). Stress: A potential Disruptor of Parent Perceptions and Family Interactions. *Journal of Clinical Child Psychology, 19*(4), 302-312.

Whitson, S., & El-Sheikh, M. (2003). Marital conflict and health: Processes and protective factors. *Aggression and Violent Behavior, 8*, 283-312.

Zimet, G.D., Dahlem, N.W., Zimet, S.G. & Farley, G.K. (1988). The Multidimensional Scale of Perceived Social Support. Journal of Personality Assessment, 52, 30-41.

APPENDIXES



A Comparison of Parental Stressors

1. Letter to Participants

Dear Sir or Madam:

I am a graduate student in the Genetic Counseling Program at the University Of South Carolina School Of Medicine. My committee and I would like to study the levels of stress that parents may experience related to rearing and caring for a child with special needs when the cause is known versus when it is unknown. In order to do so, we would like to invite parents who are members of the National Down Syndrome Society (NDSS) and have children who have been diagnosed with Down syndrom. Also, we are inviting parents who are members of Syndromes Without A Name (SWAN) with children with special needs where the cause is still unknown.

If you decide to participate, you will be asked to complete an online survey that may take some parents approximately 20 minutes. The questions in this survey will ask you about information related to your child's medical condition, treatment, services. The survey will also gather information about your views on the relationships with your child, spouse, social and emotional supports, future family plans and stress. At the end of the survey there is an opportunity to volunteer for a telephone interview to provide you the opportunity to respond with more detail to the questions that are asked during the online survey. There will also be an opportunity to enter into a drawing for a $50 gift card to Wal-Mart. You are not required to answer every question in this survey in order to participate in this drawing.

Participation is anonymous and totally confidential. The survey does not correspond in any way to your identity and if you decide to participate in the interview or drawing, no personal information will be requested so your participation will still be anonymous and confidential. The results of the study may be published or presented at academic meetings, but the participants will not be identified. When this study has been completed, we will remove the link to this survey along with all identifying information you have provided.

Your participation in this research is completely voluntary. Although you may not benefit directly from participating, your answers could help identify stressors and define ways to prevent and reduce these for other parents of children with special needs. If you are interested in participating, please fill out the survey by selecting the next button at the bottom of this page. If you decide that you do not wish to participate, you may withdraw from the study at any time without negative consequences. If you decide not to participate, just exit the survey without pressing the submit button at the end. There is also an opportunity to volunteer for an interview for more in-depth answers but you do not have to volunteer for the interview in order to complete the survey.

If you are interested in participating and have a child between the ages of 3-10, please select the Next button in order to continue. If you would like to volunteer for the telephone interview, please leave your contact information at the end of the survey and what time you would like me to call you. I ask that you complete the survey at your earliest convenience so that I may include as many participants as possible.

Thank you for your consideration. If you have any questions, you may contact your support group coordinator, my faculty advisor, or me at any time.

Sincerely,

Alicia R. Gomes, B.S.
Genetic Counseling Intern
University of South Carolina
School of Medicine
Department of OB/GYN
Suite 103

Two Medical Park
Columbia, SC 29203
(803)341-5543

Crystal Hill-Chapman, Ph.D.
Faculty Advisor
University of South Carolina
School Of Medicine
(843)661-1721

2. Drawing Entry

If you would like to enter into a drawing for a $50 gift card to Walmart please provide the necessary information below.

1. Would you like to enter into a drawing for a $50 gift card to Wal-Mart?

○ Yes

○ No

2. If you would like to enter into the drawing, please provide a first name.

3. Please provide and email address or telephone number where you can be reached.

4. Would you like to continue to the questions for this survey?

○ Yes

○ No

3. Medical Health

The following questions are geared to understand the medical health of your child. Please select the answer that best applies to your situation.

*** 1. How many children do you have?**

☐

*** 2. How many of your children have special needs?**

○ 0

○ 1

○ 2

○ 3

○ 4 or more

3. What is the birth order of your child with special needs? If you have more than one child with special needs, please check the box that applies to the child for whom you are completing this survey.

○ Only child

○ Firstborn

○ Middleborn (if not the firstborn, lastborn, or only child)

○ Lastborn

○ An identical twin

○ A fraternal twin

○ Other (please specify)

☐

4. What is the age of your child/children with special needs?

☐

5. How would you describe the severity of your child's overall health?

○ My child is in good overall health.

○ My child is in reasonable overall health.

○ My child is in less than reasonable overall health.

○ My child is in critical overall health.

○ Don't Know

6. Do you feel that your child has health problems that affect his/her wellbeing, but can be treated and managed by doctors?

○ Yes

○ No

○ Don't Know

7. Please check any that may apply. My child has problems in the following areas:

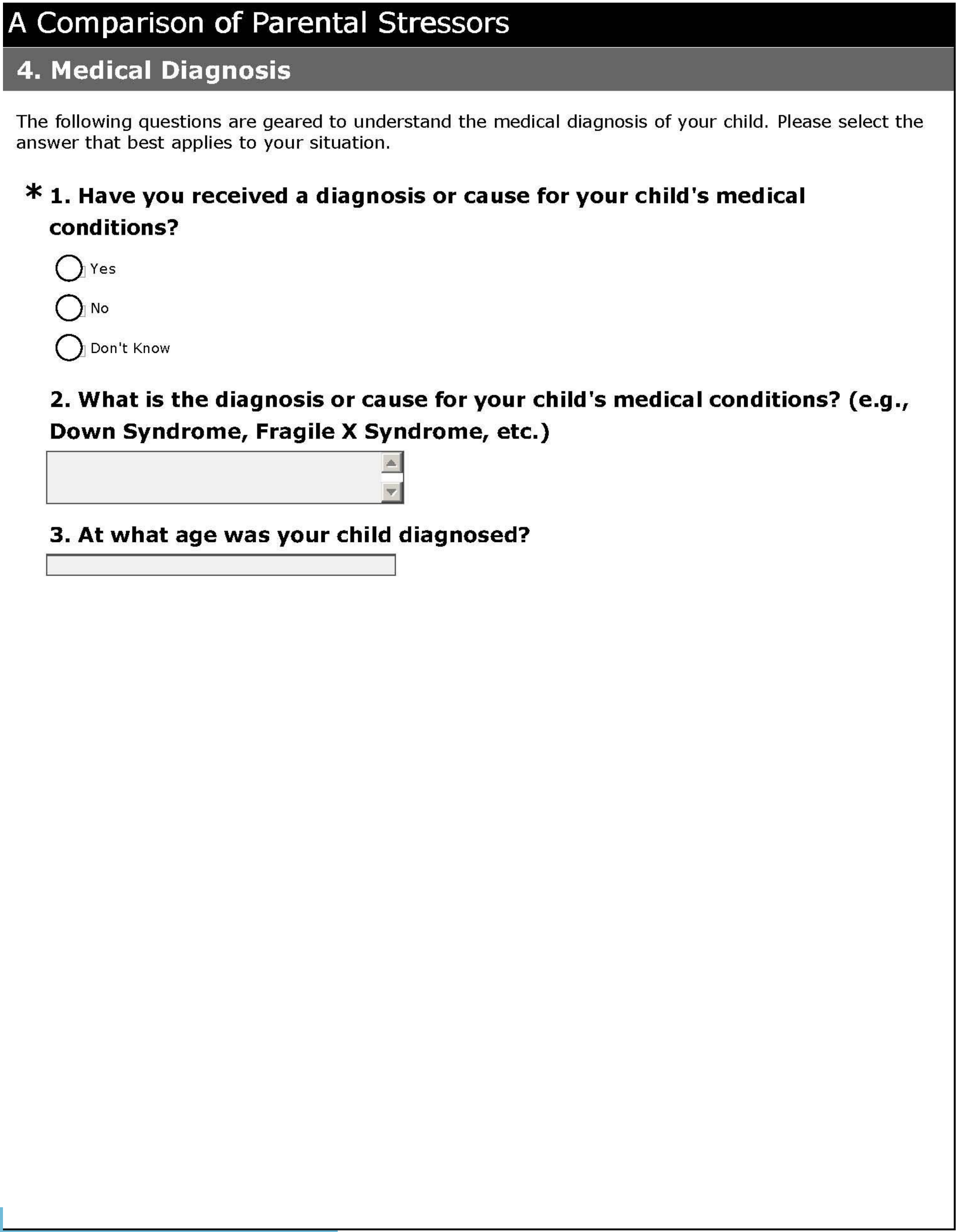
	Does Not Apply	Mild	Moderate	Severe
Hearing	○	○	○	○
Vision	○	○	○	○
Feeding	○	○	○	○
Breathing	○	○	○	○
Kidney	○	○	○	○
Urinary/Bowel	○	○	○	○
Heart Defect	○	○	○	○
Muscle	○	○	○	○
Skeletal	○	○	○	○
Seizures	○	○	○	○
Learning Disabilities	○	○	○	○
Motor Delay	○	○	○	○
Intellectual Impairment/Mental Retardation	○	○	○	○
Behavior	○	○	○	○
Speech Delay	○	○	○	○

8. Of the medical problems that you have listed for your child in question 3, which one do you consider the most significant problem?

○ Hearing
○ Vision
○ Feeding
○ Breathing
○ Kidney
○ Urinary/Bowel
○ Heart Defects
○ Muscle
○ Skeletal
○ Seizures
○ Learning Disablities
○ Motor Delay
○ Intellectual Impairment/Mental Retardation
○ Behavior
○ Speech delay

9. If your child has intellectual impairment/mental retardaton, how would you describe the severity of your child's intellectual impairment?

○ My child has mild intellectual impairment.
○ My child has moderate intellectual impairment.
○ My child has profound intellectual impairment.
○ My child has severe intellectual impairment.
○ Don't Know
○ Does Not Apply



A Comparison of Parental Stressors

4. Medical Diagnosis

The following questions are geared to understand the medical diagnosis of your child. Please select the answer that best applies to your situation.

*** 1. Have you received a diagnosis or cause for your child's medical conditions?**

○ Yes

○ No

○ Don't Know

2. What is the diagnosis or cause for your child's medical conditions? (e.g., Down Syndrome, Fragile X Syndrome, etc.)

3. At what age was your child diagnosed?

5. Medical Services

The following questions are geared to understand the medical services and therapies that your child needs. Please select the answer that best applies to your situation.

1. A syndrome is a group of symptoms that together make a specific disorder or disease. At what age did you begin seeking a syndrome name for your child's special needs?

○ Before birth because a problem was suspected on ultrasound or other prenatal test

○ Since Birth

○ Less than 1 years old

○ 1-3 years old

○ 4-6 years old

○ 7-9 years old

○ more than 9 years old

2. Do you think that you are receiving all the necessary services and therapies for your child (ex. OT, PT, government support, etc.)?

○ Yes

○ No

○ Don't know

3. What types of therapies and services are your family and child receiving?

☐ Occupational Therapy

☐ Physical Therapy

☐ Government Aid (financial assistance)

☐ Speech Therapy

☐ Home-based Therapy

☐ Sensory Integration Therapy

☐ Individual Education Program (IEP)

☐ My child does not receive any therapies or services.

☐ Other (please specify)

4. If your child has an Individualized Education Program (IEP), what is your child's special education placement?

○ Special School

○ Home Instruction

○ Self Contained

○ Resource

○ Inclusion

○ Don't know

○ Does not apply

○ Other (please specify)

6. Importance of Diagnosis

The following questions are aimed to understand your thoughts on the positive or negative effects of having a named diagnosis (i.e. Down syndrome) versus no named diagnosis to explain your child's condition. Please select the answer that best applies to your feelings.

1. In what ways do you think having a named diagnosis for your child's condition could be of benefit to your child/family?Please check all that apply.

☐ A diagnosis makes it easier to receive therapies/services.

☐ A diagnosis gives a cause for my child's special needs.

☐ A diagnosis would reduce my level of guilt for my child's special needs.

☐ A diagnosis gives insight to the future my child will have.

☐ A diagnosis affects the treatment of my child's special needs positively.

☐ A diagnosis makes my child more accepted in my community.

☐ A diagnosis makes it easier to find social and emotional supports.

☐ A diagnosis does not have any benefits.

☐ Don't know.

☐ Other (please specify)

2. In what ways do you think having a named diagnosis for your child's condition could negatively affect your child/family? Please mark all that apply.

☐ A diagnosis makes it harder to receive services/therapies.

☐ A diagnosis means my child would be labelled.

☐ A diagnosis increases my level of guilt for my child's special needs.

☐ A diagnosis limits the future for my child.

☐ A diagnosis affects the treatment my child's special needs negatively.

☐ A diagnosis makes my child less accepted in my community.

☐ A diagnosis makes it harder to find emotional and social supports.

☐ A diagnosis does not have any negative effects.

☐ Don't know

☐ Other (please specify)

3. In what ways do you think NOT having a named diagnosis for your child's condition could be of benefit to your child/family? Please check all that apply.

☐ Not having a diagnosis makes it easier to receive services/therapies.

☐ Not having a diagnosis means my child would not be labelled.

☐ Not having a diagnosis reduces my level of guilt for my child's special needs.

☐ Not having a diagnosis opens the future for my child.

☐ Not having a diagnosis affects the treatment my child's special needs positively.

☐ Not having a diagnosis makes my child more accepted in my community.

☐ Not having a diagnosis makes it easier to find emotional and social supports.

☐ Not having a diagnosis does not have any benefits.

☐ Don't know

☐ Other (please specify)

4. In what ways do you think NOT having a named diagnosis for your child's condition could negatively affect your child/family? Please mark all that apply.

☐ Not having a diagnosis makes it harder to receive services/therapies.

☐ Not having a diagnosis means my child would be labelled.

☐ Not having a diagnosis incerases my level of guilt for my child's special needs.

☐ Not having a diagnosis limits the future for my child.

☐ Not having a diagnosis affects the treatment my child's special needs negatively.

☐ Not having a diagnosis makes my child less accepted in my community.

☐ Not having a diagnosis makes it harder to find emotional and social supports.

☐ Not having a diagnosis does not have any negative effects.

☐ Don't know

☐ Other (please specify)

7. Future Family Planning

The following questions are designed to understand your personal feelings about your future family planning. Please select the answer that best applies to your situation.

1. Do you plan to have more children in the future?

○ Yes

○ No

○ Don't know

2. If you do not plan on having more children, which of the following statements apply to your situation? Please mark all that apply.

☐ I have reached my ideal family size.

☐ I do not have enough money for another child.

☐ My doctor advised me not to have more children.

☐ I need too much time to take care of this child.

☐ There is already too much stress in my marriage.

☐ That would not be fair to my other children.

☐ I do not want to take the chance of having another child with the same condition.

☐ Don't Know

☐ Other (please specify)

3. Do you feel that you are at risk for having a child with the same condition in a future pregnancy?

○ Yes

○ No

○ Don't Know

4. If yes, what do you feel is your risk of having a child with the same condition in a future pregnancy?

○ Very high

○ High

○ Medium

○ Low

○ None

○ Does not apply

5. Have you had more children since you first suspected that your child was diagnosed with special needs?

○ Yes

○ No

6. If it were possible to accurately test for your child's condition before birth, would this affect your decision to have more children?

○ Yes

○ No

○ Don't Know

7. If it were possible to test your child’s condition before birth, would you want this information in your next pregnancy?

○ Yes

○ No

○ Don’t know

8. If yes, how would this information be helpful? Please mark all that apply.

☐ For reassurance

☐ Emotionally prepare

☐ Inform family

☐ Make arrangements for the birth and medical care

☐ Termination of the pregnancy

☐ Unsure

☐ Does not Apply

Other (please specify)

8. Future Family Planning, Cont.

1. If no, please explain why you do not think you would want to test your next pregnancy.

9. Parental Stress

The following questions are designed to determine your parental stress level. For each question, think about your child/children with special needs and select the response that best represents your opinion.

1. I feel that I am

○ a very good parent

○ a better than average parent

○ an average parent

○ a person who has some trouble being a parent

○ not a very good at being a parent

2. I have found that getting my child to do something or stop doing something is

○ much easier than I expected

○ somewhat easier than I expected

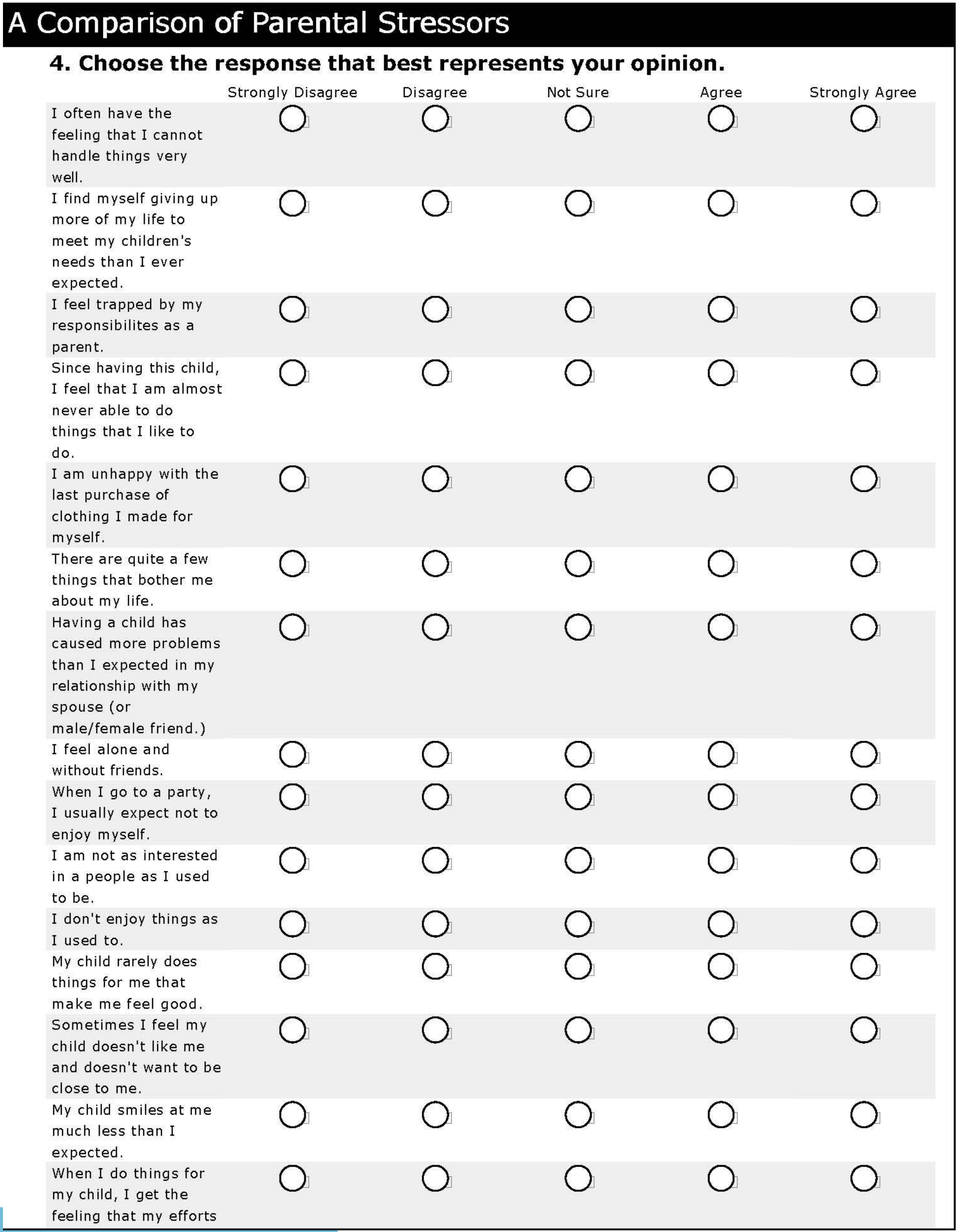
○ about as hard as I expected

○ somewhat harder than I expected

○ much harder than I expected

3. Think carefully and count the number of things that your child does that bothers you. (example: refuses to listen, overactive, cries, interrupts, fights, whines, etc.)

	1-3	1-3	4-5	4-5	6-7	6-7	8-9	8-9	10+	10+
Choose your response from the choices "10+" to "1-3." For example, if only 2 things bother you, select 1-3.	○	○	○	○	○	○	○	○	○	○



A Comparison of Parental Stressors

4. Choose the response that best represents your opinion.

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
I often have the feeling that I cannot handle things very well.	○	○	○	○	○
I find myself giving up more of my life to meet my children's needs than I ever expected.	○	○	○	○	○
I feel trapped by my responsibilites as a parent.	○	○	○	○	○
Since having this child, I feel that I am almost never able to do things that I like to do.	○	○	○	○	○
I am unhappy with the last purchase of clothing I made for myself.	○	○	○	○	○
There are quite a few things that bother me about my life.	○	○	○	○	○
Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend.)	○	○	○	○	○
I feel alone and without friends.	○	○	○	○	○
When I go to a party, I usually expect not to enjoy myself.	○	○	○	○	○
I am not as interested in a people as I used to be.	○	○	○	○	○
I don't enjoy things as I used to.	○	○	○	○	○
My child rarely does things for me that make me feel good.	○	○	○	○	○
Sometimes I feel my child doesn't like me and doesn't want to be close to me.	○	○	○	○	○
My child smiles at me much less than I expected.	○	○	○	○	○
When I do things for my child, I get the feeling that my efforts	○	○	○	○	○

are not appreciated very much.					
When playing, my child doesn't often giggle or laugh.	○	○	○	○	○
My child doesn't seem to learn as quickly as most children.	○	○	○	○	○
My child doesn't seem to smile as much as most children.	○	○	○	○	○
My child is not able to do as much as I expected.	○	○	○	○	○
It takes a long time and it is very hard for my child to get used to new things.	○	○	○	○	○

5. Choose the response that best represents your opinion.

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
I expected to have closer and warmer feelings for my child than I do and this bothers me.	○	○	○	○	○
Sometimes my child does things that bother me just to be mean.	○	○	○	○	○
My child seems to cry or fuss more often than most children.	○	○	○	○	○
My child generally wakes up in a bad mood.	○	○	○	○	○
I feel that my child is very moody and easily upset.	○	○	○	○	○
My child does a few things which bother me a great deal.	○	○	○	○	○
My child reacts very strongly when something happens that my child doesn't like.	○	○	○	○	○
My child gets upset easily over the smallest things.	○	○	○	○	○
My child's sleeping and eating schedule was much harder to establish than I expected.	○	○	○	○	○

6. Choose the response that best fits your opinion.

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
There are some things my child does that really bother me alot.	○	○	○	○	○
My child turned out to be more of a problem than I expected.	○	○	○	○	○
My child makes more demands on me than most children.	○	○	○	○	○

10. Marital Satisfaction

Please indicate below the approximate extent of agreement or disagreement between you and your parter for each item.

* 1. Marital Status

- ○ Single, never married
- ○ Married
- ○ Seperated
- ○ Divorced
- ○ Widowed
- ○ Long Term Relationship
- ○ Other (please specify)

☐

2. Choose the item that best fits your opinion. How often do you and your spouse/partner agree?

	Always Agree	Almost Always Agree	Occassionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree
Philosophy of life	○	○	○	○	○	○
Aims, goals, and things believed important	○	○	○	○	○	○
Amount of free time spent together	○	○	○	○	○	○

3. How often would you say the following events occur between you and your partner?

0= never
1= less than once a month
2= once or twice a month
3= once or twice a week
4= once a day
5= more often

	0	1	2	3	4	5
Have a stimulating exchange of ideas	○	○	○	○	○	○
Calmly discuss something together	○	○	○	○	○	○
Work together on a project	○	○	○	○	○	○

4. The numbers on the following scale represent different degrees of happiness in your relationship. The middle point (3), represents the degree of happiness of most relationships.

	0 Extremely Unhappy	1	2	3 Happy	4	5	6 Perfect
Choose the number that best describes the degree of happiness, all things considered, of your relationship	○	○	○	○	○	○	○

5. The questions below concern what happens between you and your spouse, whether your spouse is your child's other parent or your child's stepparent. While you may not find an answer that exactly describes what you think, please circle the answer that comes closest to what you think. YOUR FIRST REACTION SHOULD BE YOUR ANSWER.

SA= Strongly Agree
A= Agree
NS= Not Sure
D= Disagree
SD= Strongly Disagree

	Strongly Disagree	Disagree	Not Sure	Agree	Strongly Agree
My child's other parent enjoys being alone with our child.	○	○	○	○	○
During pregnancy, my child's other parent expressed confidence in my ability to be a good parent.	○	○	○	○	○
When there is a problem with our child, we work out a good solution together.	○	○	○	○	○
My child's other parent and I communicate well about our child.	○	○	○	○	○
My child's other parent is willing to make personal sacrifices to help take care of our child.	○	○	○	○	○
Talking to my child's other parent about our child is something I look forward to.	○	○	○	○	○
My child's other parent	○	○	○	○	○

pays a great deal of attention to our child.					
My child's other parent and I agree on what our child should and should not be permitted to do.	○	○	○	○	○
I feel close to my child's other parent when I see him/her play with our child.	○	○	○	○	○
My child's other parent knows how to handle children well.	○	○	○	○	○
My child's other parent and I are a good team.	○	○	○	○	○
My child's other parent believes I am a good parent.	○	○	○	○	○
My child's other parent makes my job of being a parent easier.	○	○	○	○	○
My child's other parent sees our child in the same way I do.	○	○	○	○	○
My child's other parent and I would basically describe our child in the same way.	○	○	○	○	○
If our child needs to be punished, my child's parent and I usually agree on the type of punishment.	○	○	○	○	○
I feel good about my child's other parent's judgement about what is right for our child.	○	○	○	○	○
My child's other parent tells me I am a good parent.	○	○	○	○	○
My child's other parent and I have the same goals for our child.	○	○	○	○	○

11. Social support

The following questions are designed to gather your feelings on your social supports. Please select the answer that best fits your opinion.

1. We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

	Very Stongly Agree	Strongly Agree	Mildly Agree	Neutral	Mildly Disagree	Strongly Disagree	Very Strongly Disagree
There is a special person who is around when I am in need.	○	○	○	○	○	○	○
There is a special person with whom I can share my joys and sorrows.	○	○	○	○	○	○	○
My family really tries to help me.	○	○	○	○	○	○	○
I get the emotional help and support I need from my family.	○	○	○	○	○	○	○
I have a special person who is a real source of comfort to me.	○	○	○	○	○	○	○
My friends really try to help me.	○	○	○	○	○	○	○
I can count on my friends when things go wrong.	○	○	○	○	○	○	○
I can talk about my problems with my family.	○	○	○	○	○	○	○
I have friends with whom I can share my joys and sorrows.	○	○	○	○	○	○	○
There is a special person in my life who cares about my feelings.	○	○	○	○	○	○	○
My family is willing to help me make decisions.	○	○	○	○	○	○	○
I can talk about my problems with my friends.	○	○	○	○	○	○	○

12. Demographics

The following questions are general questions to determine who is filling out the survey.

1. What is your age

○ <18

○ 18-25

○ 26-30

○ 30-39

○ 40-49

○ 50-59

○ 60+

2. Person filling out this survey

○ Mother

○ Father

○ Guardian

○ Other (please specify)

☐

3. Race/ethnicity

○ African-American/Black

○ White, non-hispanic

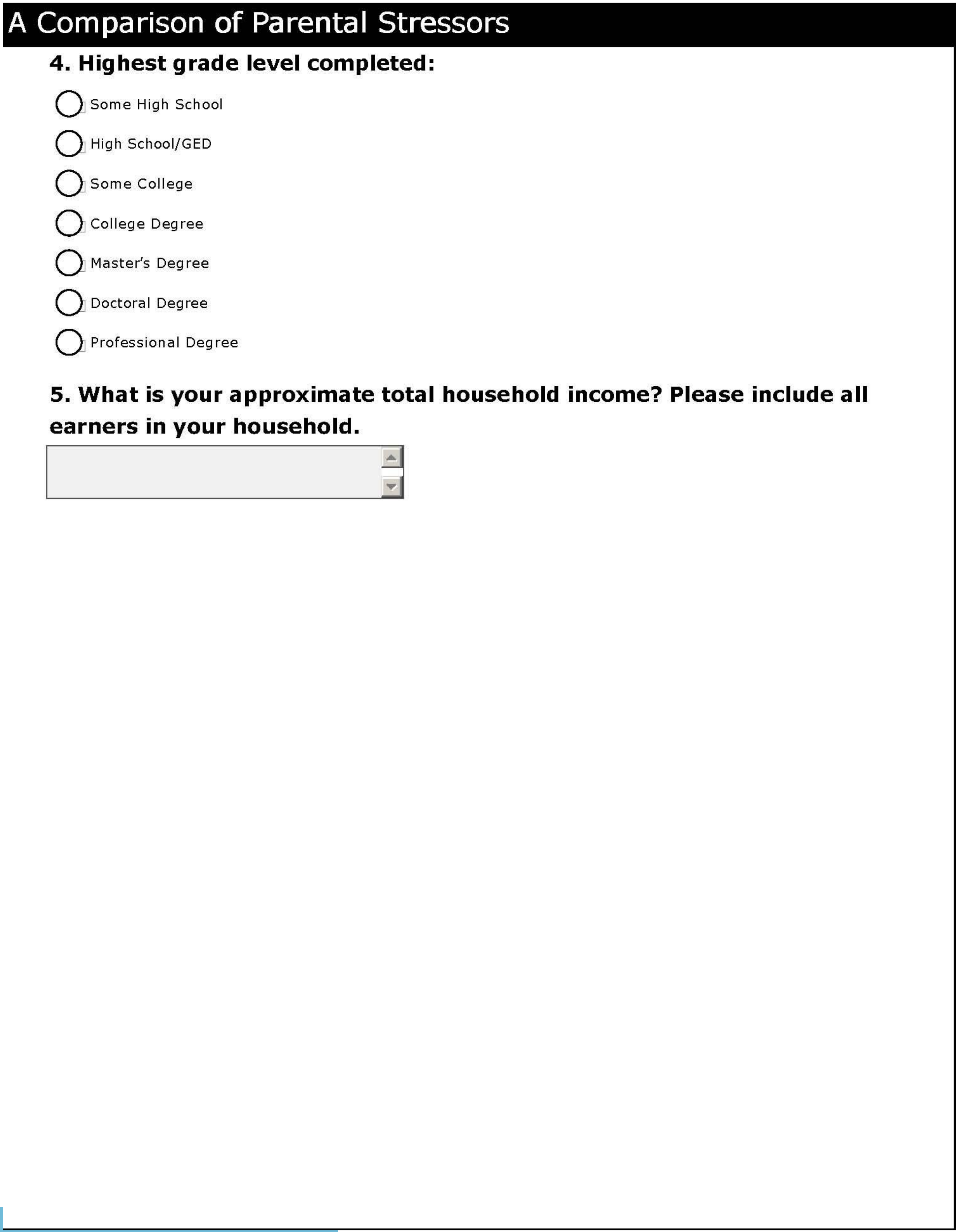
○ Hispanic

○ American Indian

○ Asian/Pacific Islander

○ Other (please specify)

☐

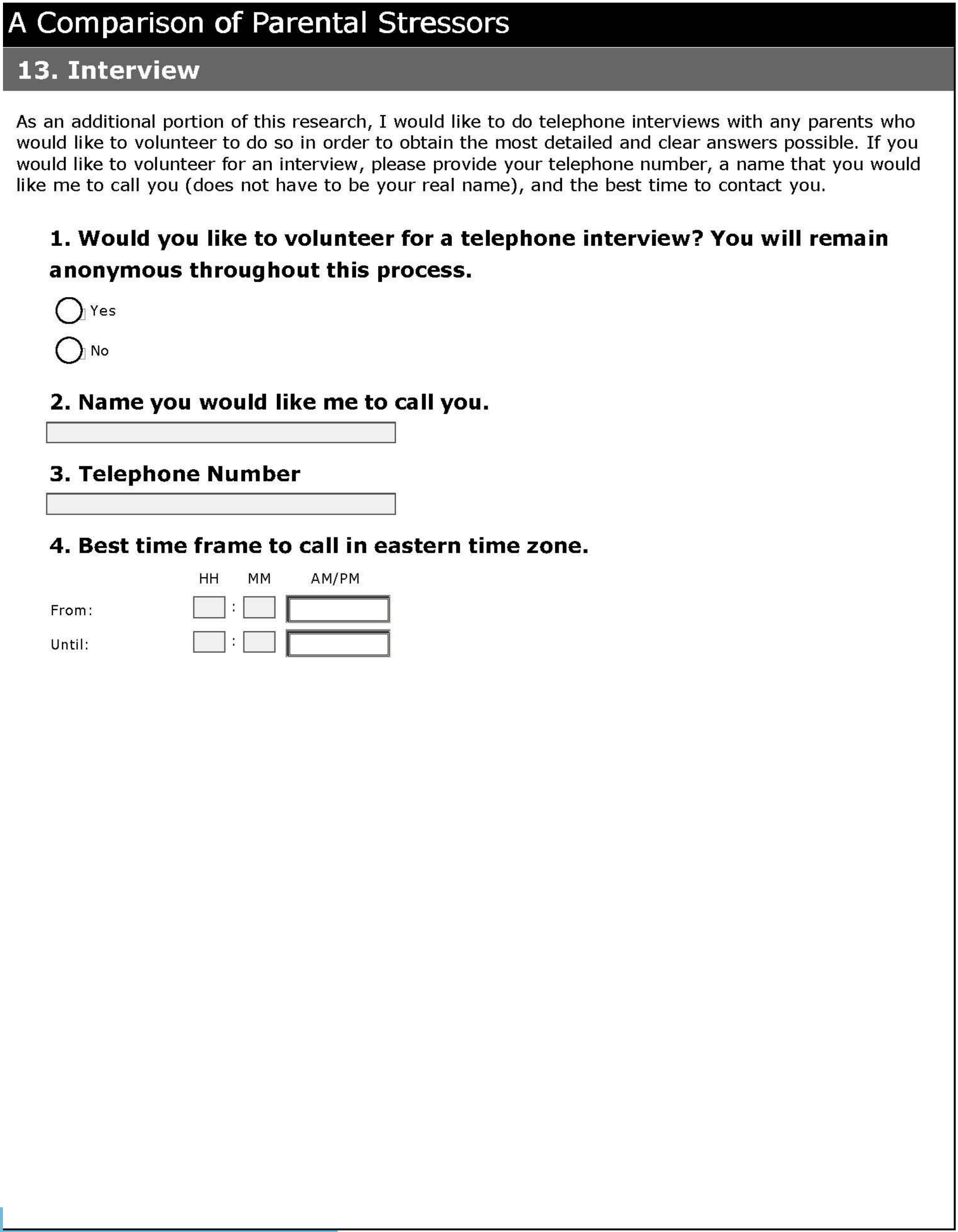


A Comparison of Parental Stressors

4. Highest grade level completed:

- ○ Some High School
- ○ High School/GED
- ○ Some College
- ○ College Degree
- ○ Master's Degree
- ○ Doctoral Degree
- ○ Professional Degree

5. What is your approximate total household income? Please include all earners in your household.



A Comparison of Parental Stressors

13. Interview

As an additional portion of this research, I would like to do telephone interviews with any parents who would like to volunteer to do so in order to obtain the most detailed and clear answers possible. If you would like to volunteer for an interview, please provide your telephone number, a name that you would like me to call you (does not have to be your real name), and the best time to contact you.

1. Would you like to volunteer for a telephone interview? You will remain anonymous throughout this process.

○ Yes

○ No

2. Name you would like me to call you.

3. Telephone Number

4. Best time frame to call in eastern time zone.

	HH	MM	AM/PM
From:	☐	☐	☐
Until:	☐	☐	☐

14. Thank you.

Thank you for taking the time to feel out this survey. Your opinions have been very valuable and appreciated.

Appendix 3. Qualitative Questions

The Child

1. Tell me about your child.
2. When did you notice that something was different about your child?
3. I would like to clarify some information from your survey questions.
4. What are you most worried about for your child __________?

The Marriage

1. Tell me about your marriage.
2. How has having your child ____ impacted your relationship?
3. Do the two of you spend time together away from your child/children?
4. Describe your parenting style. Describe your partner's style. Do you ever disagree?
5. How do you resolve differences within your marriage? Have you and your spouse seen a marriage counselor?

Future Family Planning

1. Has having ___________ changed your decisions for family planning? How?

Parental Stress

1. Tell me about your daily life. What causes you the most stress? Finances?
2. What aspect of rearing your child has caused you the greatest amount of stress?

Having a Diagnosis

1. What do you feel is the greatest benefit of having /not having a diagnosis for your child's special needs?

2. What do you feel is the greatest negative of having/not having a diagnosis for your child's special needs?
3. If your situation was reversed, how do you feel your life would change if you did not have/had a diagnosis for your child's special needs?

Supports

1. Who and/or what do you use for support? What provides you the greatest amount of support?

Personal Health

1. Tell me about what you do for your personal health. How often take out time for yourself?