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LOMA LINDA UNIVERSITY
School of Behavioral Health
in conjunction with the
Department of Counseling and Family Sciences

A Needs Assessment of Caregiving Parents to
Children with Substantial Disabilities

by

Liza Marie Garcia, M. A.

Project submitted in partial satisfaction of
the requirements for the degree
Doctor of Marital and Family Therapy

September, 2015

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in space and quality, as a project for the degree of Doctorate of Marriage and Family Therapy.

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ABSTRACT

A Needs Assessment of Caregiving Parents to Children with Substantial Disabilities

by

Liza Marie Garcia

Doctor of Marital and Family Therapy, Graduate Program in Behavioral Science
Loma Linda University, September 2015
Dr. Douglas Huenergardt, Chairperson

Parents who have a child with substantial disabilities have two distinct roles, parent and caregiver. This study sought to understand how parental and caregiver roles require distinct skills, attitudes, and behaviors that are affected by the concept of parental ambiguous loss. Using boundary ambiguity as a predictor of ambiguous loss, this study quantitatively explored levels of ambiguous loss experienced by caregiver parents. Results showed that ambiguous loss, as exhibited through boundary ambiguity positively correlated with levels of depression, and anxiety, but was negatively correlated with levels of parental efficacy, parental satisfaction and familial/friend social support. The results of this needs assessment provided a quantitative gauge of boundary ambiguity among caregiver parents that currently did not exist. Based on these results, a pilot intervention was developed to improve individual and family resilience. The results of this needs assessment will potentially inform the larger systems that attempt to provide timely support and auxiliary resources to caregiver parents.

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ABBREVIATIONS

BA ^c	Boundary Ambiguity in Family with Chronically Ill Children
BAI	Beck Anxiety Inventory
BAS	Boundary Ambiguity Scale
BDI-II	Beck Depression Inventory
IBM	Intel-based Macintosh
IRB	Internal Review Board
LVN	License Vocational Nurse
MFT	Marital and Family Therapist
MFTI	Marriage and Family Therapy Intern
PDF	Portable Document Format
PSOC	Parenting Sense of Competence
SFPRC	San Gabriel Pomona Regional Center
SPSS	Statistical Package for the Social Sciences
SSB	Social Support Index

CHAPTER 1

INTRODUCTION

Caregivers experience complicated grief and loss while caring for a family member (Boss, 2011; Schuengel et al., 2009; Ha, Hong, Seltzer, & Greenberg, 2008; White & Klein, 2008; Berge & Holm, 2007). This type of complicated grief and loss is referred to as *ambiguous loss* (Boss, 1999). Ambiguous loss is "... unclear loss resulting from not knowing whether a loved one is... absent or present... with an incongruence between the psychological family and the physical family... freezing the grief process" (Boss, 1999). Although there is a fair amount of literature on ambiguous loss among caregivers who are not parents (Boss, 1999, 2002, 2007, 2011), there is little empirical validation of the ambiguous loss experienced by the caregiver parents who have a child with severe disabilities (Berge & Holms, 2007). Additionally, no literature exists that examines the correlations between ambiguous loss and the negative consequences associated with being a caregiver parent.

This study was aimed towards understanding the multi-level dynamics associated with being a caregiver parent. For that reason, two theories were integrated that are typically not associated with each other, ecological systems theory and ambiguous loss theory. These theories usually stand-alone and have some differences, however the theoretical integration offered greater potential to be a more realistic gauge of understanding what caregiver parents experience on a regular basis. Furthermore, the existing research on caregiver parents emphasizes predominately qualitative methodology. This qualitative research explained the implications of the dual roles of parent and caregiver when caring for their child with severe disabilities (Snell & Rosen,

1997), historical accounts of ‘ambiguous loss’ experienced by the caregiver parent (Snell & Rosen, 1997; Schuengel et. al., 2009) and the questions which measures ambiguous loss understood through boundary ambiguity for caregiver parents (Berge & Holm, 2007).

Programs developers typically need quantitative data to easily explain effectiveness of a program. Therefore it seemed reasonable to take those questions (Berge & Holm, 2007) and adapt them into a quantitative survey to gauge levels of ambiguous loss as understood through boundary ambiguity among caregiver parents. This survey would then allow an all-quantitative needs assessment to be conducted that builds on previous qualitative research. Quantitative measures of the known risk factors to caregiver parents, i.e. depression (Berge & Holm, 2007), anxiety (Boss, 2011), physiological strain (Lach, Kohen, Garner, Brehaut, Miller, Klassen, & Rosenbaum, 2009), parental satisfaction and a lack of perceived parental efficacy and social support (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006), were used in correlation to the ambiguous loss theory understood by the boundary ambiguity survey in this needs assessment. This was done intentionally to gauge the differentiating levels of risk among caregiver parents. Quantitative measures were administered online to caregiver parents. The parents were identified by San Gabriel/Pomona Regional Center (SFPRC) as a caregiver to their child with severe disabilities who resides in their home. Accounting for instrument fatigue, caregiver parents were allowed one week to complete these measures.

Purpose

In this needs assessment, "family caregiver" refers to the caregiver of a family member other than a child, while "caregiver parents" refers to the parent in the dual role of providing at-home care to a child with a chronic illness and/or developmental disabilities. Family therapy researchers have sought to understand the experiences of caregivers for decades, and the most predominant area of research has focused on the family caregiver role. A significant amount of research has been done on family caregivers in a general sense; however, only a minimal amount of work exists regarding the caregiver parent. In addition to being the least researched, caregiver parents are among the most vulnerable of caregivers due to issues directly related to the care of the child. Numerous studies of caregiver parents have shown that, compared to family caregivers and parents of typically functioning children, caregiver parents are more vulnerable to a variety of negative consequences. These life consequences are directly related to the duality of the caregiver and parental roles, and can include divorce (Price, 2011), isolation (Schuengel et al., 2009), depression and anxiety (Boss, 2011; Berge & Holm, 2007), and physiological medical issues in the parent (Ha, Hong, Seltzer, & Greenberg, 2008).

Price (2011) stated that a contributing factor to the vulnerability of caregiver parents is the lack of distinction between the parental and caregiver roles. For example, when a typically functioning child falls ill, the caregiver role for the parent is usually limited in scope and time. Family caregivers are not usually expected to encompass the caregiver duties into the familial role, as these two roles are looked at with distinction. For caregiver parents, there is no distinction, no typical trajectory of development and no

limit in scope and time. Caregiver parents are expected to absorb the caregiver duties into the parental role and subsequent responsibilities indefinitely (Schuengel et al., 2009).

This expected absorption of the dual roles presents an enormous burden on the caregiver parent's parental role. Therefore, more research is needed to develop a greater understanding of the underrepresented and at-risk population of caregiver parents.

In this needs assessment, the caregiver parent roles were examined. The assessment built on previous research exploring the negative consequences of encompassing the roles of parent and caregiver for caregiver parents. Specific outcomes of interest were the relationships between reported levels of boundary ambiguity correlated to the reported levels of known negative consequences related to caregiver parents, i. e. depression (Berge & Holm, 2007), anxiety (Boss, 2011), physiological strain (Lach, et al., 2009), parental satisfaction and a lack of perceived parental efficacy and social support (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006).

Background

In her research on family caregivers, Boss (2002) examined the consequences of the acquisition of the new role of caregiver. She found that assuming the caregiver role was more stress inducing than losing a role. That is, she examined how it is more stressful to care for an aging relative than to lose an aging relative. Boss (1999, p. 53) stated, "... of all the losses experienced in personal relationships, ambiguous loss is the most devastating because it remains unclear, indeterminate." Since caregiver parents are not usually given a typical developmental trajectory, the child's disabilities are inherently ambiguous. No research has quantitatively examined the levels of ambiguity associated

with the negative consequences caregiver parents experience with the acquisition of the dual role.

Previous research in the United States has been done in this area qualitatively focusing on the parent's reaction to a child's diagnosis (Brobst, Clopton & Hendrick, 2009; Schuengel et al., 2009; Ha, Hong, Seltzer, & Greenberg, 2008; White & Klein, 2008) and the impact the diagnosis has on the parent (Berge & Holm, 2007; Epstein et al., 2007; O'Brien, 2007; Roper & Jackson, 2007; Mullins et al., 2002). There are several factors that can hinder caregiver parents from understanding what the experience of having a child with a severe disability entails; however, a quantitative examination of these factors has not been done.

Nancy Thaler (2014), the National Association of State Directors of Developmental Disabilities Services Director, reported that 1 in 20 households in America have at least one child residing in the home with a diagnosed severe disability. Locally, over 5,000 households within the San Gabriel/Pomona Regional Center (SGPRC) service area have at least one child in the home with a diagnosed severe disability (SGPRC monthly transparency report, 2014). SGPRC is one of 11 regional centers servicing Los Angeles County, with 21 regional centers servicing all of California. The Lanterman Developmental Disabilities Services Act, known as the Lanterman Act, was passed in 1969. It is a California law guaranteeing people with developmental disabilities and their families the right to access services and supports they need to live lives equal to people without disabilities. Regional centers serve as stewards of the Lanterman Act.

Currently, there are no evidence-based programs, interventions, or therapies to assist the regional centers in supporting caregiver parents. Mental health interventions targeting the negative consequences associated with the ambiguous loss experienced by caregiver parents are also unavailable. It has been hypothesized that a qualitative measure of ambiguous loss could be beneficial in the development of therapeutic interventions for caregiver parents (Berge & Holm, 2007). However, quantitative benchmark levels of ambiguous loss experienced by caregiver parents have not been established or researched. Consequently, appropriate auxiliary resources for intervention preventing or lessening the frequency of negative consequences among caregiver parents currently do not exist.

Objectives

This aim of this study was to contribute to the existing body of work by conducting a quantitative needs assessment that measured the impact that the dual roles of caregiver and parent has on parents who are caregivers of children with severe disabilities. An expectation to expand the scope of understanding among researchers of family caregivers in general to include the emotional process a caregiver parent experiences from a quantitative perspective was also an important part of this study. First, a framework of similar grief responses among family caregivers and caregiver parents who care for family members residing in the home were presented. Second, differentiating levels of ambiguous loss among caregiver parents were measured to establish benchmarks distinguishing normative levels from more severe levels of this grief response. Third, associated outcomes of depression, physiological health issues, anxiety, social support, and parental efficacy correlated with the experience of

complicated grief in caregiver parents were measured. This needs assessment also provided tool for identifying when it is necessary to employ auxiliary resources for caregiver parents. Finally the findings of this needs assessment were used to develop the program *Turning Pitfalls into Stepping Stones*.

Rationale

Presently, the literature on caregiver parents (Berge & Holm, 2007) is limited. The focus of the few studies that exist are restricted to the qualitative experience of boundary ambiguity with no distinctions of the parent and caregiver roles (Price, 2011). Additionally, the current literature on boundary ambiguity places emphasis on the experiences related to boundary ambiguity rather than the correlation between boundary ambiguity and pre-established negative consequences for caregiver parents. To understand these correlations, the theoretical lens of this needs assessment was focused on ecological systems theory and ambiguous loss theory.

The impact of the dual role of the caregiver parent were examined through the quantitative outcomes of this needs assessment. Another important subject that has not been resolved in the literature is whether boundary ambiguity is correlated with the negative consequences of being a caregiver parent. A correlation has already been established for family caregivers within the literature (Boss, 2011), allowing the outcomes of this needs assessment to bridge the gap to include caregiver parents.

CHAPTER 2

CONCEPTUAL FRAMEWORK

Caregiver parents are at risk of being emotionally vulnerable due to the continued ambiguity surrounding the child's diagnosis (Berg & Holms, 2007; Boss, 1999).

Caregiver parents also possess a uniqueness that demands a level and intensity of involvement with their child due to the duality of the parent and caregiver roles.

Typically, health professionals tend to pathologize caregiver parents who seem to be over involved in the care of their children, labeling the caregiver as enmeshed (Boss, 2011). In part, this typical misunderstanding of caregiver parents has been attributed to the health professionals being triggered by personal fears regarding sickness of their children, or children of relatives, or by anger towards a caregiver parent for not providing what the health professional feels is appropriate care for that child (McDaniel, Hepworth, & Doherty, 1992). McDaniel, Hepworth, & Doherty (1992) also noted that caregiver parents will have constant contact with health professional and need health professionals to understand the systemic consequences of these dual roles. Taking these factors into consideration is what led this researcher to ecological systems theory, and ambiguous loss theory as theories relevant for understanding the caregiver parent.

Ecological Systems Theory

Ecological systems theory, first developed by Bronfenbrenner in 1977, hypothesized that a child's development was influenced by four environmental systems, the micro-, meso-, exso-, and macro-systems, then added a fifth system in 2001, the chronosystem (Bronfenbrenner, 2005). The microsystem is an individual's body, genetic

makeup, and emotional and cognitive abilities, making a child's own biology the first primary source as an influential environment. The parents of a child have an impact on the child's microsystem but the child also has an impact on the parents, described by Bronfenbrenner (2005) as the parent-child bi-directional influence.

The mesosystem is the next layer of influence on a child's life. The family, the religion of the family, the church the family attends, the school the child attends and the relationship the parents have with teachers and anyone else directly involved in the child's development. This layer furnishes the conjunctions between the structures of the child's microsystem. It is important to note that there is reciprocity of influences on all levels within this system that has a significant impact on the child but that the child's response to this system also impacts that system. This is similar to the parent-child bi-directional influence in the microsystem.

The exosystem is the larger social system the child does not operate in directly. It is the part of a child's life that is in interaction with some structure in her microsystem. This would be something along the lines of types of grocery stores that are in the child's community, types of work schedules the child's parents are able to have, and different resources within the child's community which could have either a negative or positive effect on the child depending on the extent of their involvement. For example, if the child's parents want to eat organic food but do not live in an area where there are grocery stores that stock organic food, it now is a larger issue than just the families' choice of eating organic food, it is now interrelated to the area in which they live.

The macrosystem, which can be considered the outermost layer of a child's environment is comprised of cultural values, customs and laws. Bronfenbrenner (2005)

stated, “the macrosystem consists of the overarching patterns of the micro-, meso- and ecosystem’s characteristic of a given culture, subculture, or other broader social context” (p.149). Issues that may arise within this system that effect the child’s development have to deal with the cascading influence throughout the other systems. This system is how the child will function and view themselves in the context of a larger cultural and societal view.

The last addition, the chronosystem (Bronfenbrenner, 2005), is the dimension of time and its influence on the child. Bronfenbrenner (2005) explained it as developmental changes triggered by life events and experiences that may have originated externally in their environment or within the organism. The critical feature of such events is that they alter the existing relationship between the person and the environment, instigating change either short term or long term. As a grand systems theory, ecological systems theory looks at all of the systems that are influential in a child’s life. Looking at the context and how a clinician can help improve the process of the caregiver parents role is what all of these systems emphasize. Remaining in a frame of mind that allows for all of these systems to be considered when working with clients is part of the systemic perspective that is ingrained in the field of MFT.

The relevance to caregiver parents is that currently there is little research done with regards to the parent-child bi-directional influences from the perspective of the parent and the child’s influence on the parent (Bronfenbrenner, 2005). Bronfenbrenner (2005) stated, “No society can long sustain itself unless its members have learned the sensitivities, motivations, and skills involved in assisting and caring for other human beings” (p.14). In the ever present larger systems, like the medical systems the caregiver

parents have involvement with for as long as their child has disabilities, which in most cases is basically forever (McDaniel, Hepworth, & Doherty, 1992), is why the ecological systems theory is an essential lens.

Bronfenbrenner (2005) briefly discussed the importance of the parent-child bi-directional influence as an important part of understanding the child through the perspective of the parents. Understanding the parents influence on the child, Bronfenbrenner (2005) address how the parents reacted, engaged, loved and cared for the child would inform a child about themselves on many levels, at many different times, within the typical trajectory of development of that child. The parent-child bi-directional influence towards a child with severe disabilities would also have the same influence.

There are similarities within these theories but the major difference is that the ecological systems theory looks at the influences of systems on the individual while Boss's (2011) theory of ambiguous loss and boundary ambiguity focuses on the familial experience of caring for the individual. This is what sets Boss's theory apart from the ecological systems theory, as it is a systemic perspective, but draws attention to the caregiver's experience and not the patient's. It was what Bronfenbrenner (2005) discussed as the other side of the parent-child bi-directional influence that has not been researched extensively with parents or with caregiver parents. The needs assessment proposed by this researcher will help to quantify the bi-directional effect within this population by allowing for the previous research to guide the use of the assessments used to find the degree of co-relations between boundary ambiguity and depression, anxiety, stress, parental satisfaction and social supports.

Ambiguous Loss Theory

Boss (1999) theorized that ambiguous loss is loss that remains unresolved. The ambiguity freezes the grief, which could potentially prevent cognition, thus blocking coping and decision's-making processes. Boundary ambiguity was defined as "a state in which family member are uncertain in their perception about who is in or out of the family and who is performing what roles and tasks within the family system" (Boss & Greenberg, 1984, p.536). Berge & Holm's (2007) study explained these constructs best.....they stated that one of Boss's contributions to family stress theory is the introduction of two new constructs: ambiguous loss and boundary ambiguity. These constructs are key components of family stress theory and are founded on the premise that meaning and perception are of vital importance in determining how families respond to stressful events or situations.

An ambiguous loss is a situation in which information is unclear or unavailable, for example, a child's life expectancy may be unknown because of a severe type of epilepsy. Boundary ambiguity refers to the family's response to this ambiguous loss, for example a parent feeling like a nurse for their child rather than a mother or father. Boundary ambiguity can stem from an ambiguous loss therefore it is important to understand the construct of ambiguous loss when addressing boundary ambiguity. An ambiguous loss is a situation in which a family member cannot get clear or definitive facts about the situation.

Since caregiver parents are not usually given a typical developmental trajectory, the child's disabilities are inherently an ambiguous loss. Also because ambiguous loss

often continues indefinitely, those who experience it report that they become physically and emotionally exhausted from the relentless ambiguity (Boss, 1999, 2002).

This is supported by McDaniel, Hepworth, & Doherty, (1992) who stated that, “In families who adapt poorly to a child’s illness or disability, patterns of denial and unresolved grief often prevent the family from adjusting to accommodate to a new reality. They do not make a place for the illness in their life, and inevitably they do not accept the health professionals who also have entered their lives” (p.225).

Boss (1999) explained how living with the paradox of psychologically absent/physically present, referred to as ambiguous loss, is how to adjust to the new reality of caring for a chronically ill person. Berge & Holm (2007), theorized that the issues surrounding parenting a child with a chronic illness carries with it boundary ambiguity and ambiguous loss. Caregiver parents are faced with the decision of how to include their child with severe disabilities into their family. This type of familial adjustment is referred to as boundary ambiguity by Boss & Greenberg (1984).

Ambiguous loss involves a mismatch between physical and psychological absence/presence and can occur when a family member is physically absent but psychologically present. Examples include a family member who is missing in action, a family member who is missing due to a natural disaster or has been kidnapped or a child that was given up for adoption (Boss, 2002) another type of ambiguous loss is having a family member who is physically present but psychologically absent examples of such loss include family doing with illness such as Alzheimer's disease and stroke. Most caregiver parents also fit the second type of ambiguous loss.

Boss and Greenberg (1984), Identify the two dimensions of boundary ambiguity

(a) expectations about who does what within the family and (b) perception of who is included in the family and who is excluded. These two dimensions were referred to as role ambiguity and membership ambiguity. Role ambiguity refers to internal family boundaries, who is responsible for what within the family, where as membership ambiguity refers to external family boundaries, the line between the family and the outside world. Boundary ambiguity in caregiver parents is unclear expectations about the performance of parental roles within the family (role ambiguity) and unclear perceptions about whether the child with severe disabilities is psychologically included in the family, (membership ambiguity).

Boundary ambiguity can result from factors outside or inside the family. Outside the family the family maybe unable to acquire the facts surrounding the ambiguous situation. Inside the family, family members may have the facts surrounding event, but they may nor denied he sucks in this case interpretation of reality is a source of ambiguity. Furthermore boundary ambiguity is a continuous variable, and the degree of boundary ambiguity includes both external and internal sources of ambiguity. A basic premise is that it is ambiguity, rather than the event itself, that predicts the familial level of stress.

Boundary ambiguity applies across a variety of chronic health conditions and the degree of boundary ambiguity is influenced by key factors of health conditions. A high degree of uncertainty associated with the condition will lead to more boundary ambiguity and fatal illnesses, particularly ones that are diagnosed at birth, are more likely to lead to problems with psychologically incorporating the child into the family. What sets these constructs apart from the ecological systems theory is that an ambiguous loss and

resulting issues related to boundary ambiguity focuses on the caregiver parent and not the child.

Berge & Holm (2007) talked about how the techniques for managing boundary ambiguity created by Boss (2002) would be useful for therapists to help families who care for a chronically ill child or parent a child with severe developmental disabilities. These techniques are 1) perception sharing, 2) labeling the problem, 3) gathering information, 4) reconstructing, and 5) dialectical thinking (Boss, 2002).

Ambiguous loss, understood through boundary ambiguity, would be the most relevant theory to work with caregiver parents. The ecological systems theory (Bronfenbrenner, 2005) suggests that the context of the bi-directional influence be apart of the conceptualization of parents with a child who is chronically ill. These issues are key components in Boss's (1999) theory. Boss (1999) is the first to coin the phrase of ambiguous loss and boundary ambiguity.

Boss's ability to operationalize the experiences of caregivers to chronically ill family members is what is so ground breaking with regards to her theory. However, Boss does not address the parental issue of caregiving, as there are unique components that are not found in any other type of caregiver situation. Berge and Holm (2007) do a very good job at making sure that the caregiver parents' experience of providing care to their child is looked through this theoretical lens and suggests ways to allow for the theory to be operationalized to include research and techniques useful for caregiver parents.

Caregiver Parents are involved in many systems. Bronfenbrenner's (2005) ecological system's theory identifies influences of the outside systems on a child but also the parent-child bi-directional influence, which is supported in regards to caregiver

parents (Berge & Holm, 2007; Boss, 1999; McDaniel, Hepworth, & Doherty, 1992).

There are similarities within these theories which relate to MFT's working with caregiver parents but the major difference is that the ecological systems theory look at the influences of systems on the individual but Boss's (2011) theory of ambiguous loss understood through boundary ambiguity focuses on the familial experience of caring for the individual with an illness or disability.

Fit

It is the integration of these theories that seems the most relevant to working with caregiver parents. The therapists cannot help rebuild a family story for caregiver parents if they do not look for ways the caregiver parents thought about life in the past and how that picture is different for the caregiver parents' current reality (Deatrck, Knafl, & Walsh, 1988). Issues of complicated grief can then be addressed so long as the therapy sessions are done where the caregiver parents do not feel vulnerable, so doing this in a medical setting would not be optimal (McDaniel, Hepworth, & Doherty, 1992).

Issues that do not address the cultural context of the family in relation to the disability will not allow for the grieving process to begin (McDaniel, Hepworth, & Doherty, 1992). The therapist needs to be aware that this is not just the ethnic culture, but also the social culture and the time in which the disability was incurred. This is the step towards integrating these three theories. Looking at the micro-, meso-, exo- macro- and chronosystem, finding the issues relating to the child's biological, psychological and social needs and dealing with ambiguous loss and boundary ambiguity with the caregiver parents is the best possible way to formulate an accurate treatment plan for these families.

The focus on ecological systems level would be the mesosystem and the exosystem when dealing with the issues of ambiguous loss and boundary ambiguity Bronfenbrenner (2005) stated that the mesosystem and the exosystem are common to each other because they both deal with two or more systems and that the bidirectional orientation exists in all of the levels of the system. Boss's theory has integrated components built into its theories but fits into the ecological systems theory because they look at a family and how the family relates to the larger systems they are involved with due to their child's severe disabilities.

Bronfenbrenner, (2005) stated that he was interested in what makes parents resilient but little research has been developing to look at what the overall experience of a parent-child relationship will have on the parents and their overall functioning. The integration of the three theories could help in answering what Bronfenbrenner felt as the future of our field. The issues that are likely to keep a parent mired in hopelessness are not the child's disabilities but the ambiguity surrounding the disability. This has been explored with stories from parents who said that the not knowing what to do for, with, and to their child is what makes being a caregiver parent the most difficult process they have ever gone through (Snell & Rosen, 1997) but they were willing to learn what it takes to get them to a point of not just surviving but also thriving (Ellenwood & Jenkins, 2007).

This researcher has looked to these theories to find a new way to integrate the experience of the caregiving parent and the relational impact this has on the family. It is the issues of ambiguity that make the relational process of the familial functioning more difficult to achieve for caregiver parents. As a society we are not comfortable with

ambiguities (Boss, 2011), we like to know how things are working and what we need to do in order to fix them when they are not (Engel, 1962).

When dealing with caregiver parents it is important to remember the larger social context of comfort levels of ambiguities so that all systems interrelated with the family are addressed when working as an MFT with these families. When a family comes in to an office with a child with severe disabilities, it is important to remember the concepts of these three theories so that a detailed history is taken, compliance is addressed, and issues regarding complicated grief are also looked at. It is common that a caregiver parent will come into an MFT's office and they do not feel they have any emotional issues regarding their child with severe disabilities because they do not see the relational issues which are inherent in being a caregiver parent (McDaniel, Hepworth, & Doherty, 1992). Even more alarming is, per the caseworker's report at regional centers in California and Price (2011) estimate divorce is at 85% for these families by the time the child with severe disabilities is between the ages of 7-10 years old. It isn't simply due to the fact that these families have added stress, responsibilities and financial burdens; there are emotional underling issues that are constantly infiltrating the parental relationship (Berge & Holm, 2007).

Price (2011) goes on to state that there are many different issues that caregiver parents have to face that other families do not and this is more evident when they are going through the divorce process. As MFT's are getting to be involved in different professional areas at a much higher rate, such as mediation, medical collaborative care, etc., it is important to understand the dynamics that are taking place with these families. Conceptualizing the caregiver parents by integrating the theories of ecological systems theory and ambiguous loss theory, understood by boundary ambiguity, allows an MFT to

keeping in mind the importance of all the systems that are at play within these families.

Equally important is the emotional underlining responses to the ambiguity of the child's diagnosis, issues of ambiguous loss, boundary ambiguity and the families relationship with the health care providers. This needs assessment could potentially have the function of developing programs that will help all professionals, but particularly MFT's, to identify the ranges caregiver parents fall into with regards to boundary ambiguity and understand the potential risk factors for that particular range.

MFT's are in a unique position of being trained as systemic thinkers in the field of behavioral health, so the process of integrating these three theories would be a useful way to understand caregiver parents. It is important to note that at this time there is not such integration, however the current research suggests a need of a better understanding of the caregiver parents. It is the hope of this researcher that this will be done. The proposed integration of these theories for this needs assessment is the first step towards operationalizing interventions for caregiver parents.

The implications of this needs assessment will allow for these interventions to potentially be evidenced based when utilizing the boundary ambiguity range for this population and continually finding co-relational ranges.

CHAPTER 3

REVIEW OF LITERATURE

The majority of qualitative research has supported the hypotheses that caregiver parents experience higher levels of stress (Price, 2011), higher levels of depression and anxiety (Schuengel et al., 2009), lower levels of parental satisfaction and efficacy (Roberts & Lawton, 2001), and various levels of boundary ambiguity (Boss, 2011; Berge & Holm, 2007). Therefore it is important to address previous researched findings when considering how to conduct a needs assessment that looks at this information in a quantitative way.

Implications of the dual roles of parenting and caregiving

Parents who are also caregivers to their child with severe disabilities have a higher stress level than parents of typically functioning children (Brobst, Clopton & Hendrick, 2009; Ha, Hong, Seltzer, & Greenberg, 2008; Berge & Holm, 2007; Ellenwood & Jenkins, 2007; Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2007; Mullins, Aniol, Boyd, Page, & Chaney, 2002; Roberts & Lawton, 2001; Baile, 1989; Deatrck, Knafl, & Walsh, 1988). A major contributing factor to the heightened stress level of caregiver parents is the lack of distinction between the parental and caregiver roles (Price, 2011). Family caregivers historically have been allowed to carry both the family and caregiver roles as two separate roles (Boss, 1999, 2002, 2007, 2011), however caregiver parents are not given such an allotment. This in part is due to the fact that anyone parenting a typically functioning child can be, and are often, referred to as a 'primary caregiver'. However this interchangeable term of parent and caregiver when discussing the parental

role of a typically functioning child leaves no room for distinction for the actual caregiver parent who is both a parent and caregiver.

Due to the lack of role distinction for caregiver parents contributing to higher levels of global stress for the caregiver parent, “Children with disabilities are more likely to see their parents divorce than are other children” (Brobst, Clopton & Hendrick, 2009, p.38). Brobst, et al. (2009) goes on to say, “Despite the variety of responses to parenting children with special needs, there are common themes. The negative consequences include a decrease in fathers’ involvement in child care and greater stress in the family environment...parents of children with special needs may have to offer not only more time, energy and resources for their child’s well-being but also offer these important qualities for a longer period” (p. 38).

Price (2011) supported all of Brobst, et al. (2009) findings, and went on the report that 85% of parents who are also caregivers to a child with severe disabilities will divorce by the time the child is between the ages of 7-10 years old, typically leaving the mother as a sole caregiver and living in poverty. This is also contributed to the lack of distinction of parental and caregiver roles. Currently the judicial system does not recognize the distinction of the two roles and does not make monetary and custodial adjustments for the two separate roles (Price, 2011). Furthermore, since there is no distinction of parental and caregiver roles, a lack of relational sustainable interventions exists when co-parenting issues arise due to divorce or dissolution of a parental relationship for caregiver parents (Price, 2011).

Tobing & Glenwick (2006) reported finding that mothers who reported a greater level of functional impairment in their children reported higher levels of parenting stress

that also correlated with elevated psychological distress for the mother. One of the protective factors against psychological distress for the caregiver parent was a greater satisfaction with social support not the number of supports, i.e. formal support, involved with the parent. In fact Tobing & Glenwick (2006) found that the more formal support involved with the parents, which is usually the case the more functionally impaired the child is, no changes were reported in the mothers psychological distress. Higher levels of parent efficacy was found to predict higher levels of psychological distress when there is more ambiguity surrounding the diagnosis and expected outcomes of the child and the child's functional impairment (Tobing & Glenwick, 2006).

These findings are congruent with a study done by Snell, & Rosen (1997), which investigated how, parents 'master the job' of parenting children with special needs. The Snell, & Rosen (1997) investigation was qualitative and gave a very detailed description from parents who seem to successfully 'master the job'. The relevance today is that it is directly correlated to the current research that suggests how caregiver parents can be resilient (Brobst, et al., 2009) and what clinicians should look for and keep in mind when dealing with caregiver parents and the levels of ambiguous loss they are experiencing (Berge & Holm, 2007). "If practitioners are unaware of the range of adaptive functioning these families have, interventions may be narrowly conceived and possible fail to capitalize on family strengths (Snell, & Rosen, 1997, p. 426)". McDaniel, Hepworth, & Doherty, (1992) talked about the ambiguity that goes along with child chronic illness as there are so many different types and variables surrounding the chronic illness, unlike those chronic illnesses dealing with adults. McDaniel, Hepworth, & Doherty, (1992) talked about the 'common' three chronic illnesses that adults get, 'cardiovascular disease

(especially hypertension, and heart disease), diabetes, and cancer (p.211)', and how there are ambiguities with any chronic illness, however there is more research, more resources and more support for the adult's 'common' three. McDaniel, Hepworth, & Doherty, (1992) discussed how chronic illness happens to so many different children, at so many different developmental phases, that the illness plays a significant role in how the family adjusts. This is similar to the Bronfenbrenner's (2005) chronosystem focus of time and how this influences the person. The ambiguity makes it difficult to tolerate the chronic illness if not resolved.

Historical Experiences of Ambiguous Loss

Snell, & Rosen (1997) explained three major components, (shared traumas, coping processes and worldview shifts), as the means that allowed these families to master parenting a child with special needs. Shared traumas were the challenges these families faced through initiation of special needs, meaning 'the process by which the family first understood that their child was going to require some medical, physical, or educational care that was out of the ordinary' (p. 429), and the everyday reminders were the most significant to participants. Coping processes were conceptualized into five major themes, (family congruency, cognitive coping, defining boundaries, and external systems management styles). Finally, worldview shifts were understood as shifts in thinking that were painful and represented a letting go of life-long beliefs in 'how things are supposed to be' (p. 437). All of these components (shared traumas, coping processes and worldview shifts) have been researched by Boss (1999, 2002, 2009) in other populations experiencing ambiguous loss. Techniques that address these components have been

developed to help other populations. The gap in the research exists with caregiver parents (Boss, 2009).

Within their role as parents, they display resilience and ability to successfully accommodate their children's special needs (Brobst, et al., 2009; Tobing & Glenwick, 2006; Snell, & Rosen, 1997). Within their roles as individuals, couples, employees, etc. is where caregiver parents typically have a harder time being resilient (Brobst, Clopton & Hendrick, 2009; Ha, Hong, Seltzer, & Greenberg, 2008; Berge & Holm, 2007; Ellenwood & Jenkins, 2007; Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2007; Mullins, Aniol, Boyd, Page, & Chaney, 2002; Roberts & Lawton, 2001; Baile, 1989; Deatrack, Knafl, & Walsh, 1988). Current research suggests that there is a correlation between caregiver parents and depression (Berge & Holm, 2007), higher stress levels (O'Brien, 2007) and lower marital satisfaction due to the ambiguities surrounding the disabilities rather than the disabilities themselves (Schuengel, et al. 2009; Ha, Hong, Seltzer, & Greenberg, 2008; Epstein, et al., 2007; Roper, & Jackson, 2007; Mullins, et al., 2002). Price, (2011) reported that due to the way larger society usually functions, where the mother takes most of the responsibility for the children, especially when they are young, caregiver parents have yet another challenge to face when parenting this type of child, as it goes against social norms to have both parents equally responsible on all levels for the child regardless of the child's age.

Ha, et al. (2008) reported that parents of children with developmental or mental health problems face multiple challenges. First will be in child care, then added financial burdens due to an insurance carrier's failure to cover the full cost of services and treatments. More stress for the parents can be attributed to their child's problematic

behavior and emotional burdens associated with the stigma of disabilities. Furthermore, grief over the recognition that the child will never achieve normative adult milestones and worry about the care of the child once the parents are gone was also reported as challenging. Kersh, et al. (2006) reported how parents are the primary managers of the family's emotional climate, therefore the parents well-being is important to the maintenance of a positive family climate especially when caring for a child with disabilities.

Quantitative Needs Assessment

For a quantitative needs assessment to capture the functioning among caregiver parents, it is important to quantitatively gauge the levels of ambiguous loss understood through boundary ambiguity they are experiencing. It is also equally important to find the correlations to the above-mentioned qualitative findings and levels of ambiguous loss in a quantifiable way. Quantitative levels will allow future services developed to not only have a theoretical background to them, but also a way to reproduce effective results that can be measured and evaluated. The need to have a tool that quantitatively assesses levels of boundary ambiguity is necessary to gauge the level of familial functioning as a whole.

Furthermore this tool would help to identify barriers that are most problematic to any caregiver parent. Understanding the different levels of boundary ambiguity among caregiver parents allows these parents to understand the factors impeding optimum familial functioning. A better understanding of at risk level of boundary ambiguity and how this is correlated to the negative consequences related to caregiver parents will also help to fill in the current gap in the literature regarding boundary ambiguity for caregiver

parents.

CHAPTER 4

METHODS

In a non-traditional format of needs assessment research, this study used an advanced quantitative method to build on previous research and explore the role boundary ambiguity has on caregiver parents. Multiple linear regression was utilized to examine the relationships among several variables (boundary ambiguity, parent stress, perceived social support, parental efficacy and satisfaction, depression, and anxiety). The aim of this study is to examine how these variables relate to one another while controlling for demographics provided, therefore a multiple linear regression was the appropriate quantitative methodology (K. Bahjri, personal communication, October 16, 2014). The object of this needs assessment is to build on previous research to support the notion that caregiver parents have two distinct roles and to understand the impact of these roles on the caregiver parent.

Hypotheses

Caregivers who are not parents experience boundary ambiguity due to the nature of the duality of roles that encompass being a caregiver and family member. The aim of this study was to quantitatively showing that this is also the same for caregiver parents.

H1: It is hypothesized that caregiver parents experience boundary ambiguity.

The next three hypotheses have been qualitatively shown to be the case for caregiver parents. Currently there is no quantitative gauge for professionals to understand at-risk levels and correlations of negative consequences within the caregiver parent population. These were objectives of this needs assessment. The next three hypotheses

attempt to provide these gauges.

H2: It is also hypothesized that the higher the caregiver parent scores on the boundary ambiguity scale, the higher the caregiver parent will score on the depression, and anxiety scales.

H3: It is also hypothesized that the higher the caregiver parent scores on the boundary ambiguity scale, the lower the caregiver parent will score on the perceived social support scale as well as the parental efficacy and satisfaction scale.

H4: Furthermore it is hypothesized that, in general, the female caregiver parent will score higher than the male caregiver parent regardless of age, gender or diagnosis of the child.

The multiple linear regression model was chosen to account for variables, such as demographics, to inform the outcomes of this study as to the type of program activities should to be developed to address the findings of this needs assessment.

Participants

The participants in this needs assessment were families that have been identified by San Gabriel/Pomona Regional Center (SGPRC) who have a child living in their natural home between the ages of 0-17, approximately 4,779 children per 2013/2014 San Gabriel/Pomona Regional Center fiscal year report, who have been diagnosed with cerebral palsy, epilepsy, and/or developmental delays. Additionally the participants in this needs assessment were selected through a convenience sample, and were selected to participate based on availability and usefulness to the study (Babbie, 2007). Using G*power analysis to find sample size with a Cronbach's alpha of 0.05, a minimum of N=111 participants was needed. However due to the large sample size, at least 10% of

the sampled population is the participant goal by the end of IRB approval in one year, which is N=480 participants.

Procedure

This researcher contacted the executive director of San Gabriel/Pomona Regional Center (SGPRC) and scheduled a meeting to inform him of the purpose and procedures of this need assessment. Following this interaction, the executive director was asked for help in recruiting participants. The executive director deferred this study to the community relation's director who then sent out letters to caregiver parents who met the criteria proposed by this study. Caregiver parents were asked to contact the researcher directly so that all information of participants remains anonymous to SGPRC. The participants were informed that the survey would be taken online and could be taken with or without assistance from this researcher.

For this study, only caregiver parents of minor children between the ages of 0-17, living in their natural homes, were of interest. Families that chose to participate were first informed that this study was a collaborative effort between Loma Linda University and SGPRC. Their participation in no way would effect their eligibility for regional center services. They were informed that several self-administered questionnaires, as well as the informed consent forms, would be filled out online.

The participants were also made aware that the researcher was available to assist in any manor necessary. Data was collected and entered into the SPSS system. Demographics included in this packet were: income levels, gender of child and caregiver parent, educational level of child, as well as the type and onset of disabilities the child

has. Through this procedure, the scale of boundary ambiguity included in this packet was normed.

Measurements

All of the scales used were supported by previous quantitative research except the Boundary Ambiguity scale. Both the Beck Depression Inventory (BDI-II) and the Beck Anxiety Inventory (BAI) are used because of possible co-morbidity of depressive symptoms. Beck & Steer (1993) stated patients with anxiety symptoms frequently complain of depressive symptoms so administering the BDI-II with the BAI is useful, particularly in ruling out suicidal risk. The Social Support Behavior Scale (SSB) is used to help professionals understand that dynamics of perceived support for parents with children who have disabilities and the differences of familial and friend support if there are any. The Parenting Sense of Competence (PSOC) is used to look at how the parent is feeling about their role as a parent and if this is in line with their higher levels goals of parenting.

The Parenting Sense of Competence scale is in Appendix A, The Boundary Ambiguity scale is in Appendix B, each of the other instruments will be attached as a PDF file as only digital copies are on hand. Follow up calls were conducted two weeks after there was initial contact and assistance was provided to the majority of the participants.

Boundary Ambiguity Scale

Assessing Boundary Ambiguity in Families with Chronically Ill Children (BA^c) is a 15- item scale developed by this researcher. Questions were originally developed by Berge & Holm, (2007) as a qualitative measure used to assess for boundary ambiguity through two subscales, role ambiguity and membership ambiguity. This researcher took Berge & Holm, (2007) qualitative questions and developed a quantitative measure similar to others developed by Boss, Greenberg, & Pearce-McCall, (1990) gauging boundary ambiguity in other populations. Role ambiguity will be assessed from the first 12 questions. Membership ambiguity is assessed from the last three questions. The total score determines the rate of the level of boundary ambiguity with each question on a 6-point scale ranging between 1 (never) to 6 (always).

The total score is provided by the sum of the all scores. The higher the score, the more that respondent perceives his or her family boundaries as ambiguous. At this time, information is being gathered concerning the interpretation of boundary ambiguity scores across varied populations. Norms must be established for each population studied. Currently, the best interpretation of scores is to examine within-sample comparisons, using central tendencies and measures of variation as well as correlations with other variables (Boss, Greenberg, & Pearce-McCall, 1990).

Parent Efficacy and Satisfaction

Parenting Sense of Competence (PSOC) is a 17-item scale developed by Gibaud-Wallston and L. P. Wandersman (1978) to assess parenting self-esteem measure through sub-scales of efficacy and satisfaction. Each item is answered on a 6-point scale ranging

from strongly disagree (6) to strongly agree (1). Scoring for Items 1, 6, 7, 10, 11, 13, 15, and 17 (which are the question in the sub-scale for satisfaction) is reversed so that, for all items, higher scores indicate greater self- esteem. Reported alpha coefficients of .82 and .70 for the Satisfaction and Efficacy scales, respectively. Satisfactory 6-week test-retest correlations for the scales and for the total score were also reported; they range from .46 to .82.

This study used the adaption of the 16-item PSOC by Johnson & Mash (1989) with Cronbach's alpha coefficients calculated for the total score and for each factor. For the entire sample, the total score (16 items) revealed an alpha of .79; the Satisfaction factor (9 items) revealed an alpha of .75, and the Efficacy factor (7 items) revealed an alpha of .76.

Social Support

Social Support Behavior Scale (SSB) is a 45-item scale developed by Vaux, Reidel and Stewart (1987) to assess five modes of possible social support, emotional, socializing, practical assistance, financial assistance, and advice/guidance, from family and friends. Each item is answered on a 5-point scale ranging from 1 (no one) to 5 (most members), for family and friend. Alphas have been reported as $>.85$. Concurrent validity was reported as good with a significant correlation to other scales that measure social support.

Depression

Beck Depression Inventory (BDI-II) is a self-administered 21-item scale updated by Beck, Steer & Brown (1996) that measures the severity of depressive symptoms listed as criteria for depressive disorders in the DSM-IV in adults and adolescents aged 13 and up. Each item is rated on a 4-point scale ranging from 0 to 3, except for items 16 and 18 which have seven possible answers to differentiate between increases and decreases in behavior and motivation. Higher total scores indicate higher levels of depressive symptomology. Reported alpha coefficient .92. Satisfactory 1-week test-retest correlation of .93 ($p < .001$). BDI-II is positively correlated to many psychological tests providing evidence of convergent and discriminant validity. Within two different samples and types of distributions of the BDI-IA and the BDI-II, the BDI-II score was significantly greater endorsing more items on the BDI-II. Factorial validity was .95 ($N=500$), .91 ($N=120$).

Anxiety

Beck Anxiety Inventory (BAI) is a self-administered 21-item scale by Beck & Steer (1988) that measures the severity of anxiety in adults and adolescents. Each item is rated on a 4-point scale ranging from 0 to 3. Higher total scores indicate higher levels of anxiety. Cronbach's coefficient alpha .92. Satisfactory 1-week test-retest correlation of .75 ($p < .001$). In the BAI manual the correlations coefficients demonstrate not only significantly but also substantially related to other accepted measures of both self-reported and clinically rated anxiety. Although most measures of anxiety have been reported to be highly related to measures of depression it was expected that the BAI would be related to the BDI-II but the correlations were found to be lower than average

($r > .50$). The BAI differentiated the type of anxiety disorder [$F(4,341)=11.57, p < .001$]. With four subscales, neurophysiological, subjective, panic and autonomic, correlated with the DSM-III-R.

Analytic Strategies

Statistical analyses was performed using IBM SPSS Statistics (Version 22; IBM Corporation 1989, 2013). Descriptive statistics are given as mean \pm standard deviation or median with minimum and maximum for quantitative variables. Cronbach's alpha were used to assess the consistency of each scale in our dataset. Bivariate statistics in the form of Pearson correlation procedure will be used to assess the correlation between the quantitative variables.

Multiple linear regression were used to assess the effect of the boundary ambiguity score on the each of the five dependent variables after adjusting for gender of the child and caregiver, child's diagnosis, income, education, age, race and ethnicity, number of children in the home and age child was diagnosed. Bivariate normality, homoscedasticity, linearity and multicollinearity will be assessed for the assumptions of multiple linear regression. Alpha was set at 0.05 significance level (K. Bahjri, personal communication, October 16, 2014).

For the boundary ambiguity scale, reliability was assessed through Cronbach's alpha. Internal consistency and structural validity were assessed through the standard deviations. The averages of the items in each dimension were assessed for a correlation with the total score. A two-factor model was assessed for fit and parsimony.

CHAPTER 5

RESULTS

San Gabriel/Pomona Regional Center (SGPRC) sent out 2230 letters (IRB PDF attachment) to caregiver parents who met these sequential criteria for service provision: Children identified as stage one, are diagnosed from ages of 0-3, and are classified as at risk of not developing on a typical trajectory. Children identified as stages two and three are diagnosed at any point before the age of 18, and are evaluated as having disabilities substantial enough to receive regional center services the rest of their lives. Participants will be families that have been identified by SGPRC who have a child with substantial disabilities, who are in the stage two or three category, living in their natural homes, between the ages of 0-17, and who were diagnosed with cerebral palsy, epilepsy, intellectual delays and/or autism.

In the letter, caregiver parents were informed that they met these criteria and were asked to voluntarily participate in the study by first contacting this researcher. This researcher corresponded through text message and/or spoke with the caregiver parent then requested an email address to provide the caregiver parent with the link to the survey. The caregiver parent then simply needed to click on the link from the email to be directed to the online informed consent page. Once consent was given, the caregiver parent had one week to complete the survey online.

Table 1 (Parental demographics for first phase) represents the 116 caregiver parents whom had participated at the time of the result analysis. The demographic questions for their child in the home who has a substantial disability are represented in Table 2 (Child demographics for first phase), with gender 1 as male and gender 2 as female.

The survey took an average of 30 minutes to complete from start to finish. IRB approval was given for a year so this study remains available for other caregiver parents to complete. Follow up phone calls to caregiver parents will be done by the family resources center associated with SGPRC to keep information of participants anonymous.

Table 1
Parental Demographics for first phase

	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Gender				
Male	16	13.79	16	13.79
Female	100	86.21	116	100
Marital Status				
Never married	14	12.07	14	12.07
Married	80	68.97	94	81.03
Divorced	22	18.97	116	100
Relationship with child who has disabilities				
Parent	116	100	116	100
Combined household income				
\$0 - \$10,000	4	3.45	4	3.45
\$11,000 - \$30,000	5	4.31	9	7.76
\$31,000 - \$50,000	18	15.52	27	23.28
\$51,000 - \$70,000	33	28.45	60	51.72
\$71,000 - \$90,000	31	26.72	91	78.45
\$91,000 - \$120,000	13	11.21	104	89.66
\$121,000 +	12	10.34	116	100
Race/Ethnicity				
Latino	91	78.45	91	78.45
Caucasian	23	19.83	114	98.28
Native American	1	0.86	115	99.14
Other	1	0.86	116	100
How many siblings live in the home, other than the child with disabilities?				
0	21	18.1	21	18.1
1	52	44.83	73	62.93
2	33	28.45	106	91.38
3	8	6.9	114	98.28
8	1	0.86	115	99.14
32	1	0.86	116	100

Table 2
Child demographics of first phase

	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Gender				
1	96	83.48	96	83.48
2	19	16.52	115	100
Diagnosis				
	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Cerebral Palsy	30	26.09	30	26.09
Epilepsy	44	38.26	74	64.35
Developmental delay	17	14.78	91	79.13
Other	24	20.87	115	100
Diagnosis - breakdown of "Other" category				
1st diagnosis Kearns- Sayre Current Propionic Acidemia	1	4.17	1	4.17
All three listed above	1	4.17	2	8.33
Autism	7	29.17	9	37.5
Developmental delay with Russel Silver Syndrome	1	4.17	10	41.67
Down Syndrome	13	54.17	23	95.83
Current educational grade level				
None	28	24.35	28	24.35
Pre-school	11	9.57	39	33.91
Pre-K	1	0.87	40	34.78
Kindergarten	10	8.7	50	43.48
1st grade	5	4.35	55	47.83
2nd grade	12	10.43	67	58.26
3rd grade	9	7.83	76	66.09
4th grade	5	4.35	81	70.43
5th grade	4	3.48	85	73.91
6th grade	4	3.48	89	77.39
7th grade	3	2.61	92	80
8th grade	6	5.22	98	85.22
9th grade	4	3.48	102	88.7
10th grade	4	3.48	106	92.17
11th grade	6	5.22	112	97.39
12th grade	3	2.61	115	100
Race/ethnicity				
Latino	96	83.48	96	83.48
Caucasian	18	15.65	114	99.13
Other	1	0.87	115	100

All four hypotheses were tested on this population. Results for each hypothesis are itemized below.

H1: It is hypothesized that caregiver parents experience boundary ambiguity.

Boundary ambiguity is experienced once the score is over 15. Any score 15 or below means the respondent answered 'never' experienced to all the questions on the scale. A score of 90 is the most severe experience of boundary ambiguity because that means the respondent answered 'always' experiences to every question on the scale. This phase of study produced scores between 23-78, (M=47; SD=12), and an interquartile range of 19. The respondents were 16 males and 100 females with only 113 completing the entire survey. The ranges for levels of boundary ambiguity experienced have been established as followed: 1-15=no boundary ambiguity, 16-36=low boundary ambiguity, 37-57=mild boundary ambiguity, 58-78=moderate boundary ambiguity, 79-90=severe boundary ambiguity. Therefore this hypothesis was confirmed and is shown in Figure 1.

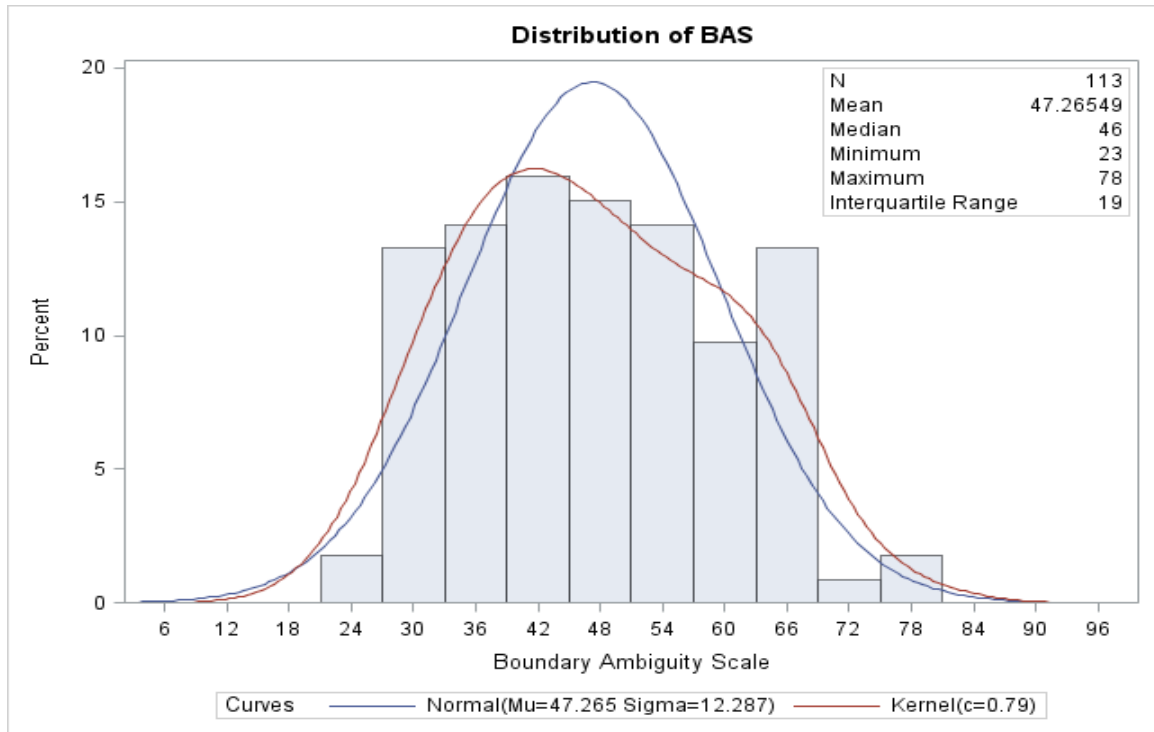


Figure 1. Distribution of Boundary Ambiguity Scale

H2: It is hypothesized that the higher the caregiver parent scores on the boundary ambiguity scale, the higher they will score on the depression and anxiety scales.

Caregiver parents experience boundary ambiguity due to the membership and role ambiguity surrounding the substantial disabilities of the child. The higher the boundary ambiguity, the higher the caregiver parent is experiencing depressive and anxiety symptomology (Berge & Holm, 2007; Boss, 2011). This study looked to confirm this hypothesis in a quantitative way, which was accomplished and is represented in Table 3. A moderately high significant correlation exists between high boundary ambiguity scores and depression ($r=0.66$, $p<.0001$) and anxiety scores ($r=0.68$, $p<.0001$).

Table 3

*Correlation of Boundary Ambiguity Score with Anxiety and Depression Scale Scores
Pearson Correlation Coefficients, N=113*

		Anxiety Score	Depression Score
Boundary Ambiguity Score	correlation	0.6817	0.6613
	Prob > r under H0: Rho=0	<.0001	<.0001

H3: It is hypothesized that the higher the caregiver parent scores on the boundary ambiguity scale the lower the scores will be on the perceived social support scale and on the parental efficacy and satisfaction scale.

The social support index looked at both family relationships and friendships. These findings showed significant negative correlations exist between boundary ambiguity scores and the social support index family relationship scores ($r=-0.38$, $p<.0001$). No significant negative correlations were found regarding friendship scores. There was a moderate significant negative correlation between boundary ambiguity scores and parental efficacy and satisfaction scores ($r=-0.51$, $p<.0001$). Therefore this hypothesis was also confirmed and shown in Table 4.

Table 4

*Correlation of Boundary Ambiguity Score with Social Support Index (with family and friends) and Parental Efficacy and Satisfaction Scale
Pearson Correlation Coefficients, N=113*

		Social Support Index: Family	Social Support Index: Friends	Parental Efficacy and Satisfaction Scale
Boundary Ambiguity Score	correlation	-0.3806	-0.29312	-0.50052
	Prob > r under H0: Rho=0	<.0001	0.0016	<.0001

However it is important to understand that it is the familial relationship that seems to be impacted by boundary ambiguity and not friendships. This in part is due to the fact that female caregiver parents find their main source of validation and support as a mother from their immediate family relationships (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Female respondents for this study represented 86% of respondents, which might explain why only the familial relationships had a negative correlation. This was one of the limitations of this study but is not uncommon in the caregiver community that females would be the majority respondents since they most often serve as the ones caring for a family member with disabilities.

H4: It is hypothesized that, in general, the family caregiver parent will score higher than the male caregiver parent regardless of age, gender, or diagnosis of the child.

In general the findings suggest there is a significant difference present when just looking at the gender of the caregiver parent in relation to their score of boundary ambiguity. Female caregiver parents scored significantly higher than male caregiver parents. This is shown in Table 5. However 86% of the respondents for this study were female making this a very uneven distribution of gender responses.

Table 5
Simple t-test of Boundary Ambiguity and Parent's Gender

Parent's Gender	Method	Mean	95% CL	Mean	Std Dev	95% CL	Std Dev
Male		38.7333	31.6989	45.7677	12.7025	9.2998	20.033
Female		48.5714	46.2157	50.9271	11.75	10.3037	13.672
Diff (1-2)	Pooled	-9.8381	-16.3619	-3.3143	11.8743	10.4967	13.671
Diff (1-2)	Satterthwaite	-9.8381	-17.17	-2.5062			
Method	Variances	DF	t Value	Pr > t			
Pooled	Equal	111	-2.99	0.0035			

Only the age of the child was a significant modifier, as shown in Figure 2.

Therefore this hypothesis is not confirmed. Furthermore, these results suggest that whenever looking at gender differences in caregiver parents, in terms of boundary ambiguity scores, the age of child needs to be indicated as well.

Model Full: Base + Child's Age + Child's Gender + Child's Dx									%change of primary effect between models
Solution for Fixed Effects									
Effect	Parent's Gender	Child's Gender	Child's Diagnosis	Estimate	Standard Error	DF	t Value	Pr > t	
Intercept				34.59	3.3509	106	10.32	<.0001	
Q4	Female			7.252	2.9636	106	2.45	0.016	26%
Q4	Male			0					
Q12mon				0.09985	0.01856	106	5.38	<.0001	
Q11		Female		-2.9963	2.6949	106	-1.11	0.2687	
Q11		Male		0					
Q13			Developmental De	-2.0247	3.2748	106	-0.62	0.5377	
Q13			Epilepsy	-3.416	2.5194	106	-1.36	0.178	
Q13			Other	-1.9935	2.9487	106	-0.68	0.5005	
Q13			Cerebral Palsy	0					
Model Base + Child's Gender									
Solution for Fixed Effects									
Effect	Parent's Gender	Child's Gender		Estimate	Standard Error	DF	t Value	Pr > t	
Intercept				39.4344	3.1183	110	12.65	<.0001	
Q4	Female			9.7093	3.2884	110	2.95	0.0039	1%
Q4	Male			0					
Q11		Female		-3.5054	2.9834	110	-1.17	0.2425	
Q11		Male		0					
Model Base + Child's Age									
Solution for Fixed Effects									
Effect	Parent's Gender			Estimate	Standard Error	DF	t Value	Pr > t	
Intercept				32.011	2.9486	110	10.86	<.0001	
Q4	Female			7.0418	2.9446	110	2.39	0.0185	28%
Q4	Male			0					
Q12mon				0.1025	0.01792	110	5.72	<.0001	
Model Base + Child's Dx									
Solution for Fixed Effects									
Effect	Parent's Gender		Child's Diagnosis	Estimate	Standard Error	DF	t Value	Pr > t	
Intercept				40.7356	3.4784	108	11.71	<.0001	
Q4	Female			10.1573	3.2777	108	3.1	0.0025	-3%
Q4	Male			0					
Q13			Developmental De	0.1256	3.5848	108	0.04	0.9721	
Q13			Epilepsy	-5.125	2.7986	108	-1.83	0.0698	
Q13			Other	-1.5533	3.3128	108	-0.47	0.6401	
Q13			Cerebral Palsy	0					

Figure 2. Checking Effect Modifications

CHAPTER 6

DISCUSSION

The purpose of this needs assessment was to quantitatively understand what caregiver parents experience in terms of boundary ambiguity and ambiguous loss. Through this needs assessment it is clear that caregiver parents are no different from other family caregivers. It has been established that family caregivers experience ambiguous loss understood by boundary ambiguity (Boss, 2011). This study confirmed the same for caregiver parents. It has been established that family caregivers report high levels of depression and anxiety (Boss, 2011). This study confirmed that caregiver parents report high levels of depression and anxiety as well.

Berge & Holm's (2007) stated boundary ambiguity was clearly present when they qualitatively used the 15 questions on the boundary ambiguity scale with their therapy clients who were caregiver parents. Boss (2011) stated that many family caregivers experience depression and anxiety but it is the ambiguity that surrounds the chronic illness that contributes to these types of mental health struggles. These mental struggles mirror the way that grief is expressed for loss of a loved one. This study confirmed the similar dynamics with caregiver parents through the boundary ambiguity scale. From these data, caregiver parents appear to experience boundary ambiguity due to the uncertainty surrounding the child's chronic condition. Bronfenbrenner's (2005) hypothesis of a parent-child bi-directional influence is relevant here as well.

Not only does the child become emotionally influenced by how the parent perceives them but the parent is influenced by the uncertainty surrounding the child's condition, therefore creating a parent-child bi-directional influence. Boss (2011) explains boundary

ambiguity this way so that family caregivers understand that, typically, the root of the mental health struggle for family caregivers is boundary ambiguity not depression or anxiety. This application of the concept is remarkably helpful to caregiving parents since it provides a reason for their emotional turmoil while also pointing to concrete actions they can begin to take. This study confirms what was hypothesized and fills in some gaps in the current research of caregivers in the general sense. Family caregivers are seen as having two distinct roles when caring for a family member.

This needs assessment supports the notion that caregiver parents also have two distinct roles when caring for their child with substantial disabilities. The implications of that notion spans across professions. However the contribution to the field of marriage and family therapy is that caregiver parents need emotional support throughout the lifespan of their child in order to continue to provide adequate care as well as continue to be a parent. The development of the Turning Pitfalls into Stepping Stones program was a direct result of the findings in this study.

First, it was confirmed that caregiver parents experience boundary ambiguity and levels of boundary ambiguity were established. The pilot program would address issues surrounding boundary ambiguity by explaining what it means to experience boundary ambiguity. Next, caregiver parents will learn ways to combat this experience and create a shift in what a family is supposed to be like. Second, when caregiver parents are experiencing boundary ambiguity they are also experiencing depressive and anxiety symptomology. This program will help create awareness to caregiver parents regarding what the difference is between symptomology and a diagnosis. The program facilitators will make sure that no one in the program is diagnosable with any mood disorder.

Third, caregiver parents feel supported when their family is involved with them on this journey of caregiving. The type and shape of family involvement will be addressed through this program. There will also be opportunities for bonds to be created among these caregiver parents. This will be done intentionally to help combat any negative consequences associated with no or little familial support.

Lastly, caregiver parent's level of boundary ambiguity goes up the older the child is. This program will provide therapeutic interventions to help caregiver parents manage this issue. The boundary ambiguity that is reported is due mostly to role ambiguity. As the child gets older and roles tend to become more uncertain, it would benefit caregiver parents to have already created a new family story that adjusts for such things. For our initial group this will not have been done but subsequent groups will target younger parents to help combat the uncertainties that will inevitably present themselves.

CHAPTER 7

PROTOTYPE PROGRAM (TURNING PITFALLS INTO STEPPING STONES)

Overview

This chapter describes the design for the prototype program, Turning Pitfalls into Stepping Stones. The pilot program will target the findings in this needs assessment. There will also be continued research produced through this program through the pre/post test phase. Looking at how to assist caregiver parents with all of their needs will be the aim of the continued research.

We as a society have been conditioned to think of things in absolutes, to have closure and to move on from loss, but this is simply a reality that does not exist for caregivers. Since the 1960's there has been this idea that closure is necessary to have in order to move on from loss. Our society has been so engrained with the need of an end to mourning that anyone who lingers in a chronic state of sorrow is abnormal. While this may seem true for the typical losses that people experience, such as a death in the family, time does not heal all things, and grief, even in the typical sense does not go away, it just visits less often.

With that said, our mindset would better equip us if we looked for meaning and not closure. In cultures, such as ours, where people believe they can always win over adversity, the skills of adaptation or compromise is devalued but adaptation and compromise are needed to maintain effectiveness in caregiving. Intentionally deciding to embrace ambiguity, remaining in charge of one's own perceptions and what being a caregiver parents mean will help caregiver parents continued journey from surviving to

thriving. The program design draws from the results from the caregiver parent quantitative needs assessment. The key principles of this program are:

1. Caregiver parents will understand ambiguous loss and how it relates to boundary ambiguity and how it is experienced.
2. Caregiver parents will be informed of the negative consequences associated with the dual roles of caregiving and parenting.
3. Caregiver parents will be given tools to help distinguish the caregiver role from the parent role.
4. Caregiver parents will learn how to manage boundary ambiguity.

Description of the Prototype Program: Turning Pitfalls into Stepping Stones

Outline

First: Intake/Resources

Caregiver parents will be provided with tailored resources to help them with their current situational needs, such as referrals to social service agencies, to help reduce any anxiety symptomology they may feel regarding caregiving their child. This will be the screening process for the parent training program as well as therapeutic services. The pre-evaluation screening process will consist of administering the survey done in this study to gather base line data of functioning. Referrals for this program will come from regional centers, physician offices, hospitals, etc.

Second: Parent Training Program, Turning Pitfalls into Stepping Stones

Caregiver Parents will participate in a 2.5 hrxwk/twelve-week training program. This program is closed to 10 to 12 parents per session to provide a safe environment to explore issues regarding parenting a child with substantial disabilities. Childcare for all children living in the home will be provided, as well as meals so that both parents are able to participate in this program. This program will typically be held in the evening so that working parents are also able to participate. The post evaluation process (all of the survey administered in this study) will serve as data for research to support the effectiveness of said training. After completion of this training program parents will be referred to therapeutic services.

Basic Format of Parent Training Program

- First Thirty Minutes: Dinner will be served and families will eat together with the LVN's and Therapist
- Next Hour and a Half: Specific topics will discussed, topics change every week.
- Last Half Hour: Group Discussion

Lastly: Therapeutic Services using the Synergetic Model (developed by this researcher)

Caregiver parents will participate in 1hrxwk therapeutic services using the synergetic model. The synergetic model uses an underlining conceptual framework's of attachment, experiential and ambiguous loss theories through an ecological systems lens.

The tools used to move the families from surviving to thriving are a combination of emotionally focused therapy, narrative therapy, and solution focused therapy. Clinicians will be trained in this modality of therapy and will be observed as well as supervised with the synergetic model in mind. The evaluation process will be the same surveys used in this study to continue to gauge levels of experiences of caregiver parents.

Participants

The program is designed to support caregiver parents were over the age of 18, who have a biological child who lives in their home, and who meet the regional center stage two or three current criteria of substantial disabilities. In addition to those who do not meet the inclusion criteria, potential participants will be screened for significant mental health issues to ensure that they will benefit from the program. It is expected that participants will exhibit some mental health symptoms such as depression and anxiety. To deal with this risk, the Turning Pitfalls into Stepping Stones program director will be a trained and certified mental health provider and has been instructed not to include individuals who identify as having severe mental health related limitations.

Length of Program and Location

Group sessions will be held for 2 1/2 hours, once a week, for 12 weeks. The location of the community building will be in Southern California.

Goals and Objectives

The goal of this program is to provide psychological, social, and emotional support for caregiver parents. The second goal of the program is to assist caregiver

parents in building a positive emotional and social community to counteract external and internal discourses regarding the known negative consequences associated with being a caregiver parent. The key components of the program are described below.

- Understanding the impact of dual roles
- The lucky number seven
- Creating any new family story

Key Components of ambiguous loss understood through boundary ambiguity

1. The content goals of a group workshop are described below.

- Understanding boundary ambiguity
- Coping with dual roles
- Understanding the need of connecting to others in the caregiving parent community
- Finding meaning in the ‘good enough’ family
- Developing a new family narrative

2. The process goals of a group workshop are described below.

- How to live with constant ambiguous situations
- Managing the emotions of the whole family
- Learning to be your own advocate

The Turning Pitfalls into Stepping Stones Program Outline

Any community building that has access for individuals with disabilities can be used to provide these services. Marriage family therapist interns (MFTI) and doctoral students in marriage and family therapy programs will be facilitators.

The Project Planning Activities are:

1. Identify the goals of the individuals attending the Turning Pitfalls into Stepping Stones program and obtain written statement of commitment to their goals in participating in the program.
2. Identify grants, sponsors, and funding for the Turning Pitfalls into Stepping Stones program.
3. Meetings will be held at secure places, such as resource centers.
4. Recruit target population from local regional center, children's hospital, physician offices and school districts.
5. An MFT will screen clients in an initial assessment.
6. Clients will file the necessary application forms.
7. An MFT will interview clients.

Upon admission, all clients will receive a program booklet that will include the project description. The project description will state the rules, including the confidentiality policies. The project population will sign all the forms, project activities, and statement of goals.

Survey Questionnaire (Pre-Test and Post-Test)

A Pre-test and Post-test packet of questionnaires will be given to the participants in order to evaluate the outcomes of the prototype program. A full copy of the questionnaires is provided as a PDF attachment. The marriage family therapist (MFT) will perform the assessments intake and a program developer will ensure that the assessment is conducted in accordance with the guidelines he or she has set. The staff will meet periodically with the program developer for supervision and continued training.

Week One: Joining

Session one: getting to know each other. This is an initial joining session where program participants and program facilitators will meet for the first time and become familiar with one another. This is a two-hour session.

The goal of Session One is to join together and to explore each others family story of how they came to be caregiver parents and what that currently means to them. This is a quick overview of the child's diagnosis, prognosis and family composition. Each family will be given a time limit that will be enforced by the facilitators.

The content goal of Session One is joining and understanding of each other's families and finding the similarities. The process goal of Session One is to determine their goals in attending the program.

The objectives of Session One:

1. Introduction of facilitators.
2. Introduction of Turning Pitfalls into Stepping Stones Program.
3. Introduction of each participant.

The methods and techniques are:

1. Participants are registered at the door and receive information brochures.
2. Participants are asked to pick a seat in the circle.
3. Each participant writes their name on a name tag.
4. Facilitators will start with their introductions and will introduce the program as well as the program rules.

Week Two: Dual roles

Session two: caregiver parents have dual roles. It may seem at times that the role of caregiver is expected if you are a parent but in reality it is a choice that is made. With that choice comes certain responsibilities that may not have been expressly known in the beginning of your journey as a caregiver, and what is not usually talked about is the loss that is experienced when you have dual roles such as this. The content goal of Session Two is to understand that with the dual roles comes a loss that is a relational loss, the loss of an important, irreplaceable relationship trajectory with their child. The process goal of Session Two are:

1. Understanding “Ambiguous Loss”, a term coined by Pauline Boss, and that this is the term associated with this type of loss. Understanding the experience of ambiguous loss is one of the best ways to turn pitfalls of caregiving into stepping stones, and possible resentment into resiliency.
2. Move the mindset of a caregiver from surviving to thriving. So often I hear and have experienced the feeling of just needing to get through the most current crisis, to simply survive what seems to be an endless struggle at times, and while this is true some of the time, we all know it is not true all of the time. So how do you move from surviving to thriving?

Week Three: Ambiguous Loss and Boundary Ambiguity

Session three: moving from surviving to thriving is understanding

ambiguous loss. Content Goal: One of the first ways at moving from surviving to thriving is understanding what ambiguous loss is because it is important for

us to have a label for what it is we are experiencing. The process goals are:

1. Think of it like a diagnosis, with out one there is no course of action that can be taken to manage the symptoms of an illness or condition.
2. The term means a loss that is unclear, there is no resolution, no closure, unlike how we think of typical loss, where there is a distinct absence, making ambiguous loss the most difficult kind of loss because there is no possibility for closure. No one will validate or support this loss as they do when someone dies, even though you feel the relational loss and you know that there is nothing that can change the relationship back to what is once was and what you had hoped it would be in the future.
3. The outcome of this loss is boundary ambiguity, meaning there is an unclear role that you and your child will play in each other's lives. This lack of clarity is why it is so hard at times to do the day-to-day things that are needed to be a caregiver. There is not a typical reciprocal exchange within this relationship and there are no guidelines as to what you can anticipate on a day-to-day basis.
4. To make sense of this type of loss you need to increase your tolerance for the stress of ambiguity. This means allowing room in your mind for two truths to be present at the same time, for instance, your child is not the child you had dreamt of but you still and care for the person they are.
5. When there is no cure of an illness or condition, the only window for hope it to become more comfortable with ambiguity and a less than perfect relationship. This also requires trust in the unknown that things will work out and that what ever happens can be managed.

6. Hope lies in understanding that you are doing the best you can and knowing that bad things can indeed happen to good, smart, hardworking people.
7. Whatever your familial goals were in the past a new goal has to be incorporated. That goal is to achieve a psychological shift or transformation in your thinking that fits a relationship that is now drastically changed by an illness or condition. This is accomplished by accepting ambiguity.

Week Four: Complications

Session four: impact the inevitable. Researchers tell us that the main cause of distress for caregivers is neither the burden of caregiving nor the severity of the illness or condition, rather the stress caused by not being able to resolve the problem, not being able to ease their loved ones suffering, not having control over their own lives anymore, not knowing what roles to play, not knowing when it will end and not knowing whether they are doing a good job, considering that there's often no positive feedback from the patient, extended family or larger community, leaving the caregiver isolated most of the time. The process goals are:

1. Impacting the inevitable isolation is the chronic sadness and mixed emotions associated with the illness or condition, making it a relational issue due to some external conditions that is outside of your control and is not your fault. There is no closure because you are constantly testing your acceptance of loss. This roller coaster of losing, finding and losing again will erode anyone's stability and strength.
2. The difference between typical grief and complicated grief is informational clarity. (give example of rituals of death, funerals, etc.) With informational

clarity there is freedom to move on with your life, without it you are in limbo with no immediate resolution. This is why understanding what kind of loss you are experiencing helps you cope and move towards acceptance of ambiguity.

3. It is important to remember that time does not heal all things, grief, even in the typical sense does not go away, it just visits us less often. There is no such thing as getting over it and our goal is not to get over it but to live with grief and to be at peace with that.
4. The two truths that are needed to be maintained in your mind are, the child you love is still alive but is not the child you thought they would be or are no longer the person he or she used to be. It is the co-existence of these two truths that needs to be accepted and grieved.
5. Allowing yourself to grieve along the way through your journey as a caregiver is important to your well being as a person. (give example of things that they will never get to do that they thought they would, like late night movie openings with a teenage child). As mentioned before, accepting ambiguity means letting go of extremes one way or the other.

Week Five: Resiliency

Session five: understanding the effect of gender. Typically woman are still the primary caregiver and they care give by doing the daily difficult and isolating tasks such as feeding, bathing, dressing, etc. There has been an increase in males who are caregivers but they typically have the responsibilities of managing the finances and arranging for care. For these reasons it is the woman caregivers who will typically report being stressed, anxious and depressed at higher level then their male counterparts. The process

goals are:

1. Woman typically use an emotion-focused coping style while men typically use a problem-focused coping style, but it has been the opinion of many professionals in the field to use some of both types of coping styles.
2. Problem-solving coping style is useful to make decisions, solve a problem, and doing precise tasks such as medication management and appointments.
3. Emotion-based coping style is useful to acknowledge feelings and through out the process of accepting ambiguity as well as grieving along the way.
4. With either coping style it is important to remember that your effectiveness depends on being positive, not ignoring despair, and believing you can manage the situation even though it is difficult.
5. Equally important is to remember that being positive does not mean that you can't have release of emotion, like crying, it means assessing your feelings regularly,
6. Barriers to being a more resilient caregiver include family conflict, stress pileup, negative judgment, isolation, cultural stigma and rigid perceptions. It is important to point out that for caregivers barriers to managing stress must be removed, this means that the caregiver must enlist help from family, their community and if possible society at large.

Week Six: The Myth of Closure

Session six: the cultural demand. A culture that values mastery and control will demand closure, a culture that denies death will demand closure, a culture that assumes we can avoid suffering will demand closure and our own anxiety about death will demand closure. The process goals are:

1. When you are a caregiver and love the person you are caring for the challenge is to balance mastery and control with acceptance.
2. Living without closure means you have to change your previous ideal of a close relationship with balanced roles and clear boundaries.
3. Relationships need to be looked at from a new perspective in order to regain balance and control.
4. Learn to live with two opposing ideas- here and gone, present and absent. Talk with your child one even if they don't answer, touch and hug them even if they don't return your gesture, these things and many others will increase your tolerance for ambiguity.

Week Seven: The Psychological Family

Session seven: the expansion of family. Family is so often thought of through biological and legal ties, but family can also be psychological, this is an important distinction for caregivers who feel alone. The process goals are:

1. The psychological family is not a replacement of a biological family but rather an expansion of it. There is an importance in having a family physically close as well as those who can mentally and emotionally support you. The term psychological means the family that we choose, the family that is created in your heart and mind. This can be made of up of all types of relationships but one key characteristic of these relationships is that there are no 'relationship needs'. This means there are no expectations on either end, love, affection, caring, advice and tangible assistance are all given without an expectation of reciprocity from both parties.

2. Sometime this week take a few minutes and think about whom you would consider as part of your psychological family.
3. We now know that our well-being is tied to our connections with other people who love and support us, as caregivers this is extremely important to prevent the inevitable loneliness that will come if you are not intentionally seeking and developing your psychological family who will be there for you doing the good and bad times.
4. Empathy is doing to others what you would want done for yourself, which is one of the reasons you are a caregiver, but it is also needed when you look at how people treat you as a caregiver and how much they are willing to empathize with you.

Clip from the movie *My sisters keeper*

Week Eight: Family Rules

Session eight: spoken and unspoken. Every family has rules that are spoken and unspoken, however there are things that can be adapted or created to fit your situation now.

Family rituals are repeated interactions, traditions and celebrations that give us a sense of closeness and belonging to a particular group. They can be grand, like how weddings are conducted and they can be small like how you say hello and good bye when a loved one leaves or returns. Family rituals are powerful organizers of behaviors within the family system and are good for mental health. The process goals are:

1. As a caregiver you may not be able to attend your family rituals but that does not mean that you cannot adapt the rituals or create new ones with your biological

and/or psychological family. One of the most detrimental things to do is to cancel family rituals altogether. Try to maintain at least a few rituals with at least one other person so that the feeling of ‘the good times are gone forever’ is not present.

2. Ambiguous loss holds both the sadness and joy you are experiencing simultaneously and both need to be acknowledged. For caregivers, rituals reveal who’s on your team and thus who will be there for you when you need help and support, they provide a visible picture of solidarity, one that can lift you up and give you the motivation to keep going.

Week Nine: The Lucky Number 7

Session nine: seven guidelines. Here is an overview of the content and process goals of the seven guidelines for your journey as a caregiver that will help you turn pitfalls into stepping stones

1. Meaning; you can live with contradictions once you acknowledge the reality of them in your life. Remember that finding meaning takes time and patience is vital.
2. Balance Control with Acceptance; to stay in control differentiates what you can control from what you cannot. When you cannot control what is going on around you, you can still master your reactions, thoughts and internal selves.
3. Broaden your Identity; besides being a caregiver, who are you and how do you maintain that part of yourself?
4. Manage your mixed emotions; mixed emotions are normal but acting on them is not. Wishing ‘it’ was over is typical but the challenge is to acknowledge and then manage such ambivalence.
5. Two Truths; you must hold on and let go at the same time, find a middle ground

6. Image new hopes and dreams; while you give care you must also picture in your mind what your future might be like
7. Take the time to mind yourself; the responsibility for your health is more than yours alone, when you need help learn to lean on your friend, neighbors and relatives

Week Ten: The New View of “Good Enough”

Session ten: valuing a less than perfect relationship. Take the moment and make the best of it even if the outcome is unclear.

1. Ambiguity opens up possibilities for human growth and strength, it allows for hope despite our having no guarantee of a desired outcome, allows for change and new opportunities, makes us grow emotionally, encourages us to be more spontaneous and improvisational in other parts of our lives. We also get time to say good-bye and work out some of our unresolved issues, and teaches us that nothing is final.
2. If there is really no silver lining, it is important for you to make a safe space in your mind where you know and even other know that you have done your best and can do no more.
3. Accepting the idea of a less than perfect relationship is not equivalent to giving up. This type of acceptance is an active decision to recognize that reality of a relationship compromised by illness or a condition. Valuing a less than perfect relationship is your choice.

Week Eleven: Self Advocacy

Session eleven: the primary caregiver parent. Make sure you are aware of the

medical professionals and they are aware of you as the primary caregiver.

1. Caregivers by definition are overly responsive, which is what your job demands, but these professionals are trained to look at you as co-dependent, enmeshed, and undifferentiated without a sense of self. While these terms are appropriate for some relationships, it is not for you as a caregiver. Society expects you to be the primary caregiver so they are not allowed to label you in a negative way.
2. It is important that you have your own doctor, someone who is trained to talk to you about all the things you are experiencing as a caregiver and can be your advocate
3. Over functioning for your child as there caregiver will be looked at in a negative light with mental health professionals, however it is important to remember that what was once considered a dysfunction in a relationship with a typical functioning child is not when you are caregiving parent.
4. The label of depression will be one that you may even give yourself at time when you are caregiving because the dynamic of caregiving will create symptoms of depression in even the strongest of people. It is important to remember that you may just be sad and that you are in an ambiguous and unbalanced relationship with your child. This requires over functioning.

Week Twelve: Creating Your New Family Story

Session twelve: the better fit. The content and process goals are the same here, Open discussion on what was presented during the last 11 weeks to help these families understand how open they can be.

Summary

One of the goals of this study was to provide a basis of measurement for a caregiver parent training program. Through quantitative measures, this study has provided a way to gauge how much boundary ambiguity the caregiver parent is experiencing and understand what is correlated emotionally when a caregiver parent experiences boundary ambiguity. This needs assessment explored the correlations and found the caregiver parents experience boundary ambiguity just as family caregivers do. This study also provided a framework of understanding the parent-child bi-directional influence (Bronfenbrenner, 2005). The results of this quantitative needs assessments were motivated towards designing a strong, systematic process program for caregiver parents. In short, this is a program that has been tailored specifically to the needs and challenges of caregiver parents and is sensitive to their experience.

Limitations and Recommendations for Future Research

One of the limitations of a quantitative needs assessment is that the validity may not be as strong as if it were a qualitative needs assessment. With that said, all the measurements in this needs assessment, except for the boundary ambiguity scale, have strong validity backing. Another limitation is that the participants of this study were selected through a convenience sampling of only families from one regional center in California. This rules out families who are not part of the regional center system. Therefore this sample will not represent the full spectrum of caregiver parents. Another limitation is that some of the instruments used to measure the variables have not been

normed for caregiver parents or even minorities.

This program has limitations as well. The program proposed is a pilot program and has been executed at this time. It would take a large amount of funding to allow participants in the program to get all of the services they would need to be successful at completing this program. However, it is an important process that needs to take place for caregiver parents.

More research needs to be done on various caregiver parents. There will also need to be more quantitative research done to continue to test the establish benchmarks for caregiver parents regarding their overall experience. It would also be prudent to replicate this same study at all 21 regional centers in California to get a clear picture of caregiver parent functioning across the state. Having both genders of parents, regardless of who the primary caregiver parent is, would also be another way to gather much needed data on this population so that causation of the correlations confirmed in this study could be potentially understood.

CHAPTER 8

CONCLUSION

To summarize, this needs assessment has developed the following recommendations for marriage family therapists as they work with caregiver parents. First, the findings confirm that caregiver parents experience boundary ambiguity. Based on that knowledge, treatment goals and interventions for caregiver parents need to include the processing of boundary ambiguity. Second, the findings emphasize the importance of understanding boundary ambiguity and the correlations associated with this experience of complicated grief.

Finding the bi-directional influence for the caregiver parents and understanding how this is expressed will drive the proper therapeutic process. Understanding that depressive and anxiety symptomology will be present when dealing with a caregiver parent is an important part of proper diagnosing and treatment planning as a rule out of any other major mood disorders. Familial social support is important for caregiver parents and is related to how successful they feel at being a caregiver parent. Therefore it is important to get caregiver parents to create friendships with other caregiver parents so that there is an infrastructure in place should there be no or little familial support.

In the pilot program, caregiver parents are encouraged to share their experiences with others to gain social and emotional support and counterbalance the negative attributions associated with being a caregiver. This process will allow caregiver parents practice in telling their story and potentially give their story less power over how they experience being a caregiver parent. Lastly, this study confirmed that the age of the child has an impact on the level of the boundary ambiguity scale scores. This also supports

Bronfenbrenner's (2005) hypotheses of a parent-child bi-directional influence.

Overall, the pilot program I have designed seeks to address the major needs of the population the study has focused on through evidence-based, clinical treatment and intervention. This study fills important gaps in research and clinical intervention approaches in current marriage and family therapy (MFT) practices by implementing a program especially for caregiver parents. The program specifically supports caregiver parents in their journey and helps distinguish between the caregiver and parental roles as well as suggests clinical and research guidelines for other marriage family therapists, healthcare providers, program developers, policy makers, and other community leaders who may be working with this population. This study and program also seeks to bridge the gaps in the research surrounding caregiver parents to provide systematic care that is based on their reported needs and sensitive to their emotional experiences.

References

- Abidin, R. R. (1983) *Parenting Stress Index* (3rd ed.) Odessa, FL: Psychological Assessment Resources, Inc.
- Babbie, E. (2007). Quantitative data analysis. *The practice of social research*. (pp. 405-425). Belmont, CA: Thomson Wadsworth.
- Beck, A. T., & Steer, R. A. (1993) *BAI Beck Anxiety Inventory Manual*. San Antonio, TX: Harcourt Brace & Company.
- Beck, A. T., Steer, R. A., Brown, G. K. (1996). *BDI-II Beck Depression Inventory Manual* (2nd ed.). San Antonio, TX: Harcourt Brace & Company.
- Berge, J. M. & Holm, K. E. (2007). Boundary Ambiguity in Parents With Chronically Ill Children: Integrating Theory and Research. *Family Relations*, 56, 123-134.
- Boss, P., & Greenberg, J. (1984). Family boundary ambiguity: A new variable in family stress theory. *Family Process*, 23, 535-546.
- Boss, P., Greenberg, J. R., & Pearce-McCall, D. (1990). *Measurement of Boundary Ambiguity in Families*. St. Paul, MN: Minnesota Agricultural Experiment Station.
- Boss, P. (1999). *Ambiguous Loss: Learning to Live With Unresolved Grief*. Cambridge, MA: Harvard University Press.
- Boss, P. (2002). *Family Stress Management: A Contextual Approach* (2nd ed.). Thousand Oaks, CA: Sage.
- Boss, P. (2007). Ambiguous Loss Theory: Challenges for Scholars and Practitioners. *Family Relations*, 56, 105-110.
- Boss, P. (2011). *Loving someone with Dementia*. San Francisco, CA: Jossey-Bass
- Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting Children With Autism Spectrum Disorders. *Focus on Autism and Other Developmental Disabilities*, 24, 38-49.
- Bronfenbrenner, U. (1970). *Two Worlds of Childhood: U.S. and U.S.S.R*. New York, NY: Russell Sage Foundation.
- Bronfenbrenner, U. & Mahoney, M. A. (1975). *Influences On Human Development*. Hinsdale, IL: The Dryden Press.
- Bronfenbrenner, U. (1979). *The Ecology of Human Development*. Cambridge, MA: Harvard University Press.

- Bronfenbrenner, U. (1989). Discovering What Families Do. In Blankenhorn, D., Bayme, S., & Elshtain, J. B., *Rebuilding the Nest* (pp. 27-38).
- Bronfenbrenner, U. (1990). The Bioecological Model From a Life Course Perspective: Reflections of a Participant Observer. In Moen, P., Elder, Jr., G. H., & Lusher, K., *Examine Lives in Context* (pp.599-618).
- Bronfenbrenner, U. (1990). Developmental Ecology Through Space and Time: A Future Perspective. In Moen, P., Elder, Jr., G. H., & Lusher, K., *Examine Lives in Context* (pp.619-647).
- Bronfenbrenner, U. (2005). *Making Human Beings Human*. Thousand Oaks, CA: Sage.
- Bubolz, M. M. & Sontag, M. S. (1993) Human Ecology Theory. In Boss, P., Doherty, D. J., LaRossa, R., Schumm, W. R., & Steinmetz, S. K., *Sourcebook of Family Theories and Methods*, New York, NY: Plenum Press (pp.419-450).
- Carroll, J. S., Olson, C. D., & Buckmiller, N. (2007) Family Boundary Ambiguity. *Family Relations*, 56, 210-230.
- Cowan, C. P., Cowan, P. A., Pruett, M. K., & Pruett, K. (2006). An Approach to Preventing Co-Parenting Conflict and Divorce in Low-Income Families: Strengthening Couple Relationships and Fostering Father' Involvement. *Family Process*, 46, 109-121
- Deatrick, J. A., Knafl, K. A., & Walsh, M. (1988). The process of parenting a child with disability: normalization through accommodation. *Journal of Advanced Nursing*, 13, 15-21.
- Derogatis, L. R. & Melisaratos, N. (1983). The Brief Symptom inventory (BSI): an introductory report. *Psychol Med*, 13, 595-606.
- Disability Rights California (2012). *California's protection and advocacy system*. Retrieved from <http://www.disabilityrightsca.org/pubs/506301index.htm>
- Ellenwood, A. E., & Jenkins, J. E. (2007). Unbalancing the Effects of Chronic Illness: Non-Traditional Family Therapy Assessment and Intervention Approach. *The American Journal of Family Therapy*, 35, 265-277.
- Engel, G. L. (1962). *Psychological Development in Health and Disease*. Philadelphia, PA: W. B. Saunders Company.
- Engel, G.L. (1996). From Biomedical to Biopsychosocial: I. Being Scientific in the Human Domain. *Family Systems & Health*, 14, 425-433.

- Engel, G.L. (1996). From Biomedical to Biopsychosocial: II. A Personal Odyssey. *Family Systems & Health*, 14, 434-44.
- Epstein, T., Saltzman-Benaiah, J., O'Hare, A., Goll, J. C., & Tuck, S. (2007). Associated features of Asperger Syndrome and their relationship to parenting stress. *Child: care, health, and development*, 34, 503-511.
- Field, A. (3rd Ed.). (2009). *Discovering Statistics Using SPSS*. Thousand Oaks, California: Sage Publications, Inc.
- Ha, J. H., Hong, J., Seltzer, M. M., & Greenberg, J. S. (2008). Age and Gender Differences in the Well-Being of Midlife and Aging Parents with Children with Mental Health or Developmental Problems. *Journal of Health and Social Behavior*, 49, 301-316.
- Hirshberger, G., Srivastava, S., Marsh, P., Cowan, C. P., & Cowan, P. (2009). Attachment, marital satisfaction, and divorce during the first fifteen years of parenthood. *Personal Relationships*, 16, 401-420.
- Johnston, C., & Mash, E. J. (1989). A Measure of Parenting Satisfaction and Efficacy. *Journal of Clinical Child Psychology*, 18, 167-175.
- Kersh, J., Hedvat, T. T., Hauser-Cram, P., & Warfield, M. E. (2006). The contribution of marital quality to the well-being of parents of children with developmental disabilities. *Journal of Intellectual Disability Research*, 50, 883-893.
- Lach, L. M., Kohen, D. E., Garner, R. E., Brehaut, J. C., Miller, A. R., Klassen, A. F., & Rosenbaum, P. L. (2009). The health and psychosocial functioning of caregivers of children with neurodevelopmental disorders. *Disability and Rehabilitation*, 31, 607-618.
- Masood, A. F., Turner, L. A., & Baxter, A. (2007). Causal Attributions and Parental Attitudes Toward Children with Disabilities in the United States and Pakistan. *Council for Exceptional Children*, 73, 475-487.
- McDaniel, S. H., Hepworth, J., & Doherty, W. (1992). *Medical Family Therapy*. New York, NY: Basic Books.
- McDaniel, S. H., Hepworth, J., & Doherty, W. (1995). Medical Family Therapy With Somatizing Patients: A Co-Creation of Therapeutic Stories. In McDaniel, S. H., Lusteran, D. D., & Mikesell, R. H., *Integrating Family Therapy* (pp. 377-388).
- McDaniel, S. H., Lusteran, D. D., & Philpot, C. I. (1995). Introduction to Integrative Ecosystemic Family Therapy. In McDaniel, S. H., Lusteran, D. D., & Mikesell, R. H., *Integrating Family Therapy* (pp. 3-17).

- McDaniel, S. H., Campbell, T. L., Hepworth, J., & Lorenz, A. (2005). *Family-Oriented Primary Care*. New York, NY: Springer Science+Business Media, Inc.
- Morgan, W. L., & Engel, G. L. (1969). *The Clinical Approach to the Patient*. Philadelphia, PA: W. B. Saunders Company.
- Mullins, L. L., Aniol, K., Boyd, M. L., Page, M. C., & Chaney, J. M. (2002). The Influences of Respite Care on Psychological Distress in Parents of Children with Developmental Disabilities: A Longitudinal Study. *Children's Services: Social Policy, Research, and Practice*, 5, 123-138.
- Neely, J., Amatea, E. S., Echevarria-Doan, S., & Tannen, T. (2012). Working with Families Living with Autism: Potential Contributions of Marriage and Family Therapist. *Journal of Marital and Family Therapy*, 38, 211-226.
- O'Brien, M. (2007). Ambiguous Loss in Families with Children with Autism Spectrum Disorders. *Family Relations*, 56, 135-146.
- Price, M (2011). Divorce Issues and The Special Needs Child. *American Journal of Family Law*, 25, 28-36
- Roper, S. O., & Jackson, J. B. (2007). The Ambiguities of Out-of-Home Care: Children with Severe or Profound Disabilities. *Family Relations*, 56, 147-161.
- Roberts, K. & Lawton, D. (2001). Acknowledging the extra care parents give their disabled children. *Child: Care, Health and Development*, 27, 307-319.
- Schuengel, C., Rentick, I. C. M., Stolk, J., Voorman, J. M., Loots, G. M. P., Ketelaar, M., Gorter, J. W., & Bechart, J. G. (2009). Parents' reactions to the diagnosis of cerebral palsy: associations between resolution, age and severity of disability. *Child: Care, Health and Development*, 35,673-680.
- Snell, S. A., & Rosen, K. H. (1997). Parents of Special Needs Children Mastering the Job of Parenting. *Contemporary Family Therapy*, 19, 425-442.
- Sperry, L., Powers, R., & Griffith, J. (2008). Biopsychosocial Issues. *The Journal of Individual Psychology*, 64, 369-376.
- Sprenkle, D. H. (2002). Physical Disorders. In Sprenkle, D. H., *Effectiveness Research in Marriage and Family Therapy* (pp.311-338).
- Sprenkle, D. H., Davis, S. D., & Lebow, J. L. (2009). *Common Factors in Couple and Family Therapy*. New York, NY: the Guilford Press.

- Tobing, L. E., & Glenwick, D. S. (2006). Predictors and Moderators of Psychological Distress in Mothers of Children with Pervasive Developmental Disorders. *Journal of Family Social Work*, 10, 1-22.
- White, J. M., & Klein, D.M. (2008). *Family Theories* (3rd ed). Thousand Oaks, CA: Sage Publications, Inc.
- Vaux, A., Reidel, S. & Stewart, D. (1987). Modes of social support: The Social Support Behaviors (SSB) Scale. *American Journal of Community Psychiatry*, 15, 209-237.

Appendix A

Parenting Sense of Competence Scale

The following statements are about your relationship with your child with a chronic health condition. Using the scale provided as a guideline, circle the number that best shows how you feel. There are no right or wrong answers. It is important that you answer every item, even if you are unsure of your answer.

For questions 1-16, use the following scale as a guide in answering:

1	2	3	4	5	6
Strongly Agree	Agree	Somewhat Agree	Somewhat Disagree	Disagree	Strongly Disagree

- | | | | | | |
|---|---|---|---|---|---|
| 1. The problems of taking care of a child are easy to solve once you know how your actions affect your child, an understanding I have acquired....1 | 2 | 3 | 4 | 5 | 6 |
| 2. Even though being a parent could be rewarding, I am frustrated now while my child is at his/her present age....1 | 2 | 3 | 4 | 5 | 6 |
| 3. I go to bed the same way I wake up in the morning, feeling I have not accomplished a whole lot.....1 | 2 | 3 | 4 | 5 | 6 |
| 4. I do not know why it is, but sometimes when I am supposed to be in control, I feel like the one being manipulated.....1 | 2 | 3 | 4 | 5 | 6 |
| 5. My parent was better prepared to be a good parent than I am.....1 | 2 | 3 | 4 | 5 | 6 |
| 6. I would make a fine model for a new parent to follow in order to learn what she/he would need to know in order to be good parent.....1 | 2 | 3 | 4 | 5 | 6 |
| 7. Being a parent is manageable, and any problems are easily solved.1 | 2 | 3 | 4 | 5 | 6 |
| 8. A difficult problem in being a parent is not knowing whether you're doing a good job or a bad one.....1 | 2 | 3 | 4 | 5 | 6 |

9. Sometime I feel like I'm not getting anything done.....	1	2	3	4	5	6
10. I meet my own personal expectations for expertise in caring for my child....	1	2	3	4	5	6
11. If anyone can find the answers to what is troubling my child, I am the one...	1	2	3	4	5	6
12. My talents and interests are in other areas, not in being a parent.....	1	2	3	4	5	6
13. Considering how long I've been a parent, I feel thoroughly familiar with this role...	1	2	3	4	5	6
14. If being a parent of a child were only more interesting, I would be motivated to do a better job as a parent.....	1	2	3	4	5	6
15. I honestly believe I have all the skills necessary to be a good parent to my child.....	1	2	3	4	5	6
16. Being a parent makes me tense and anxious.....	1	2	3	4	5	6

Appendix B

Assessing Boundary Ambiguity in Families with Chronically Ill Children

The following statements are about your relationship with your child with a chronic health condition. (As you read, imagine his or her name in the blank space in each sentence.) Using the scale provided as a guideline, circle the number that best shows how you feel. There are no right or wrong answers. It is important that you answer every item, even if you are unsure of your answer.

For questions 1-15, use the following scale as a guide in answering:

1	2	3	4	5	6
Never	Rarely	Some of the time	Most of the time	Almost always	Always

- | | | | | | | |
|---|---|---|---|---|---|---|
| 1. To what extent do you feel like a medical assistant rather than a parent to _____?..... | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. To what extent does _____ feel more like a patient than your child?..... | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. To what extent do you feel guilty doing something enjoyable for yourself given that _____ has a chronic health condition and may need your help?.... | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. How difficult is it for you to carve out your own life while _____ needs your help?..... | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. To what extent do you feel like having _____ interferes with your ability to establish and maintain friendships?..... | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. To what extent do the needs of _____ interfere with your ability to leave the home?..... | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. To what extent does having _____ interfere with your ability to take time for yourself?..... | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. To what extent does _____ needs make it difficult to attend to your own needs?..... | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. To what extent do you have disagreements with your spouse/partner about your involvement with _____?..... | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. How uncertain are you about how to discipline _____?..... | 1 | 2 | 3 | 4 | 5 | 6 |

11. To what extent are you confused about how much you should be doing for _____?.....1 2 3 4 5 6
12. To what extent are you confused about your expectations for _____ (what to expect _____to do for him/herself, what things _____should be responsible for)?.....1 2 3 4 5 6
13. To what extent do family members tend to ignore _____?.....1 2 3 4 5 6
14. Are there times when _____does not feel like your child?.....1 2 3 4 5 6
15. At times are you unsure where _____fits in as part of the family?.....1 2 3 4 5 6

Appendix C

Demographic Parent Questions

Parent/Caregiver Information Sheet

1. Gender of the parent/caregiver Male Female (Please circle one)
2. Age _____
3. Relationship to child who has disabilities Parent Legal Guardian
 Grandparent Other _____
(please write in relationsh
4. Not including the child with disabilities, how many siblings live in the home? _____
5. What range does your combined household income fall into? (Check the box that applies)
- | | | | |
|--------------------------|---------------------|--------------------------|----------------------|
| <input type="checkbox"/> | \$0 - \$10,000 | <input type="checkbox"/> | \$71,000 - \$90,000 |
| <input type="checkbox"/> | \$11,000 - \$30,000 | <input type="checkbox"/> | \$91,000 - \$120,000 |
| <input type="checkbox"/> | \$31,000 - \$50,000 | <input type="checkbox"/> | \$120,000 + |
| <input type="checkbox"/> | \$51,000 - \$70,000 | | |
5. What is your race/ethnicity? (Check the box that applies)
- | | | | |
|--------------------------|------------------|--------------------------|-----------------|
| <input type="checkbox"/> | Latino | <input type="checkbox"/> | Caucasian |
| <input type="checkbox"/> | Asian | <input type="checkbox"/> | Native American |
| <input type="checkbox"/> | African-American | <input type="checkbox"/> | Other |

Appendix D

Demographic Child Questions

Child's information

1. Gender of the child Male Female (Please circle one)
2. Age of child with chronic diagnosis _____
3. Child's diagnosis (Check the box that applies)
- | | | | |
|--------------------------|----------------|--------------------------|---------------------|
| <input type="checkbox"/> | Cerebral Palsy | <input type="checkbox"/> | Developmental Delay |
| <input type="checkbox"/> | Epilepsy | <input type="checkbox"/> | Other |
4. Age of the child's diagnosis _____
5. Child's grade level _____
6. What is the child's race/ethnicity? (Check the box that applies)
- | | | | |
|--------------------------|------------------|--------------------------|-----------------|
| <input type="checkbox"/> | Latino | <input type="checkbox"/> | Caucasian |
| <input type="checkbox"/> | Asian | <input type="checkbox"/> | Native American |
| <input type="checkbox"/> | African-American | <input type="checkbox"/> | Other |