

Running head: The up side of Down syndrome and fathering

The up side of Down syndrome and fathering:
An exploration of hope, satisfaction, and coping.

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Acknowledgements

Still have to figure this one out! 😊

Abstract

This study was founded on a non-deficit model and utilized the theory of ambiguous loss in exploring the attitudes of hope and satisfaction of fathers of children with Down syndrome (DS); both at the time when they received their child's diagnosis and at the time of data collection. Using a person oriented mixed methods approach, a cluster analysis was used to examine how attitudes of fathers may be related to coping strategies and behaviors. Three clusters were identified from the sample of 50 fathers and were subsequently named: CL1- *Hoping*, CL2- *Connecting*, and CL3- *Thriving*. Further understanding of the clusters was found as a result of the qualitative directed content analysis of text responses. The *Hoping* and *Thriving* clusters were significantly and qualitatively different from each other. The *Hoping* cluster experienced ambiguity and loss of the child they expected to have, yet, they charged ahead with an action oriented approach towards acceptance; while pushing to help their child reach their fullest potential. The *Connecting* cluster, which is the largest cluster, demonstrated a sense of cause for outreach in the DS community and were united with others by their child's diagnosis. The *Thriving* cluster was the most successful at reframing their experience and creating positive meaning in the midst of the ambiguity of their child's diagnosis; while embracing the life they are living.

Keywords: fathers; Down syndrome; coping; cluster analysis; ambiguous loss

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Chapter I

Introduction

Purpose of the Study

The purpose of this study is to create a better understanding of the experiences of fathers whose child has Down syndrome (DS). While the experiences of parents of children with developmental disabilities have been examined in previous research (Crnic, Pedersen y Arbona, Baker, & Blacher, 2009; Sanders & Morgan, 1997), research focused on fathers of children with special needs is quite minimal (Brotherson & Dollahite, 1997). Most research on parents of children with special needs continues to focus on mothers and not on the contributions or experiences of fathers (Crnic et al., 2009). This specific population of fathers of children with DS has received little attention.

Fathers make a significant contribution to their children's social, emotional, and cognitive development (see Allen & Daly, 2002 for a summary of the research). When fathers are involved in their children's lives, school aged children have higher academic achievement, exhibit better coping skills, and show signs of healthier emotional development (Rosenberg & Wilcox, 2006). In adolescence the father-child relationship has a significant impact on risk taking behaviors (Bronte-Tinkew, Moore, & Carrano, 2006). The impact of a father's acceptance or rejection of a special needs child is felt through the immediate and extended family and thus greatly influences the child's well being (Brotherson & Dollahite, 1997).

Previous Research

Despite years of research efforts relatively little is known about specific family issues related to DS (Hodapp, 2007). In a review of studies about fathers of children with a variety of disabilities, Hornby (1994) reported that there was a limited amount of credible research and that expectations for negative outcomes often expressed in the literature were not well founded. He expressed concern that the prevailing negative expectations may influence the services provided to fathers by professionals and cautioned against negative projections.

Down syndrome is a genetic abnormality caused by the presence of an extra 21st chromosome occurring in approximately one in every 690 live births (National Association for Down Syndrome, 2011). The actual prevalence of DS is unknown because a majority of prenatally diagnosed babies with DS are terminated. Nevertheless, parents appear to adjust well to the challenges connected to raising a child with DS and there even appears to be a new phenomenon identified as the Down syndrome advantage (Ricci & Hodapp, 2003; Hornby, 1994; Stoneman, 2007). This 'advantage' is a pattern of findings that indicate families of children with DS experience greater well-being than families of children with other intellectual disabilities, perhaps due to the highly sociable personalities of many people with DS (Hodapp, Ly, Fidler, & Ricci, 2001).

The Current Study

Within the framework of the theory of ambiguous loss and a non-deficit model, the current study explores the hope and satisfaction attitudes of fathers

of children with DS both at the time they when they received their child's diagnosis of DS and at the time of data collection. Specifically, the current study will examine how those attitudes related to hope and satisfaction may be related to coping strategies and behaviors.

Theoretical Framework. Loss, and the grief that accompanies it, are part of the human experience. When a loss occurs in an unclear way it does not mean that the experience of the loss is obscured, however the structures for grieving the loss are unclear. The theory of ambiguous loss, developed by Pauline Boss (1999), attempts to provide a framework for making sense of losses that are vague or ambiguous. The theory of ambiguous loss is appropriate to use when looking at men's experiences as fathers of children with DS because having a special needs child may challenge the father's psychologically anticipated construction of his family (Boss, 1999). Fathers may experience a sense of ambiguous loss as they discover the child they were expecting will have a persistent lifelong condition. A diagnosis of DS has an ambiguous outcome, the severity of impairment is not predictable and it is not a disorder that can be resolved with some form of treatment. This ambiguity may be difficult for fathers to process as they adjust their expectations to the family with which they will now live.

Perspective is powerful in framing how to observe and interpret information. Throughout the literature on the subjects related to fathering and particularly fathering children with DS, there is a consistent call for a more positive paradigm for future research (Antonovsky, 1979; Brotherson &

Dollahite, 1997; Grant, Ramcharan, and Flynn, 2007; Grzyvacz & Ganong, 2009; Hawkins & Dollahite, 1997). The framework of ambiguous loss may be helpful in identifying ways to better understand the structures and processes in these families that are supportive and generative to the strength of the family unit. In turn that information could be used to identify ways to support the families that struggle under the demands of raising a child with special needs. Research that is grounded in the theory of ambiguous loss and a positive framework could help to paint a picture for those who do not share this lived experience.

Sample. The sample for this study was recruited, via web-based DS support and information groups, to participate in an online survey. The survey instrument has both quantitative and qualitative elements and allows respondents to leave contact information for further participation.

Methodology. The analysis for this study utilized a person centered approach that has both quantitative and qualitative components (Bergman, 2000; Hsieh & Shannon, 2005). The first goal is to identify heterogeneous subgroups of fathers within the sample that exhibit differences in hope and satisfaction attitudes. These groups will then be examined for differences in coping strategies and behaviors. Finally, the text responses to the open-ended questions in the survey will be examined for a more in depth understanding of the groups.

Value of the Study

Relatively little is known about specific family issues related to DS (Hodapp, 2007). Overall, parents appear to adjust well to the challenges connected to raising a child with DS; however, previous studies have primarily focused on the stressors of parenting a child with DS (Hornby, 1994; Olshansky, 1962; Wolfensberger & Menolascino, 1970). As with many of life's challenges, raising a child with DS is stressful. The point of the non-deficit model is not to deny the stressors; it is to identify strengths and resources. The purpose of this study is to examine if hope and satisfaction play a role in a father's response to the inarguable stressor of raising a child with DS. Does hope and satisfaction in turn have any relationship to the father's coping strategies and behaviors? By using a non-deficit model, it is possible to examine what works, rather than just look at what is already known to be difficult. This non-deficit model also offers the possibility of providing a framework for developing unique offerings for future interventions that could support families faced with DS and other developmental conditions.

Chapter II

Review of the Literature and Theoretical Foundations

Conceptualization

This study is about a specific population – fathers of children with the developmental disability of Down syndrome. Fathers are important to all children and contribute to the creation of a stable supportive environment in which children grow (Rosenberg & Wilcox, 2006). This study explored how the constructs of hope and satisfaction may provide a means to understand how these fathers are coping with their experiences. First, various aspects of the father role are reviewed to understand how it may be influenced by having a child with DS. Then the constructs of hope, satisfaction, and coping are explored. Finally, the theory of Ambiguous Loss is reviewed as a framework for developing a non-deficit model of hope and satisfaction to capture a better understanding of this group of fathers (Boss, 1999, 2007).

Due to the perception that having a special needs child was bad, almost every study prior to the 1980s featured a negative paradigm that anticipated poor outcomes for families (Hodapp, 2007). More recent work has framed having a child with DS more like any other stressor that families face (Hodapp, 2007). There is inadequate research on the effects of DS versus other forms of disability, and even less research that delineates between mothers' and fathers' experiences (Hodapp, 2007; Skotko, 2005). We do know more about fathers of children with disabilities in general than specifically about fathers of children with DS (Hodapp, 2007). Hornby (1994) calls for soundly designed empirical

studies to comprehensively understand the wide range of perspectives of fathers' experiences at different stages of their own and their children's development.

Brotherson and Dollahite (1997) echo the call for more research of fathers of children with special needs, with a further call for the use of a generative type model. Grant, Ramcharan, and Flynn (2007), in exploring resilience in families with members who have special needs, call for a better understanding of meaning-making and the symbolic importance that may be attached to elements of everyday life in theoretically framed research. The salutogenic (Antonovsky, 1990), non-deficit (Grant et al., 2007), and generative (Brotherson & Dollahite, 1997) models are examples of theoretically driven models that offer the commonality of a positive paradigm for research. For this study, the theory of ambiguous loss will provide the framework for a non-deficit model of research as it examines how fathers cope with the ambiguous situation of having a child with DS.

To better understand the contextual aspects of this study the literature in the areas of DS, fathering, marital roles, and the work-family interface are reviewed. Furthermore the literature on the constructs of hope, satisfaction, and coping are explored. Finally, literature on the theory of ambiguous loss is presented in order to identify how it frames this study.

Context

Down syndrome. Although there are nearly 1,000 genetic-chromosomal disorders, DS is the most commonly occurring, on average 1 of every 690 live

births; the majority of children born with DS are born to mothers under 35 years of age (NADS, 2011). Most individuals with DS have mild to moderate mental and motor impairments. None the less, they are more like other children than they are different, and they express varied talents and gifts which need encouragement (NADS, 2011). Children with DS also often face an assortment of health impediments to which parents and caregivers must attend. The most common is congenital heart defects, but infections, vision and hearing problems, and thyroid conditions are also frequent concerns (NADS, 2011).

Life span studies are beginning to reflect changes in the lifestyles of families with a member with a disability (Hodapp, 2007). Since the turn of the 21th century more children with disabilities are being educated in fully integrated classrooms in the public schools (Buckley, Bird, & Byrne, 1996, as cited in Hodapp, 2007). Individuals with DS are now living longer, are better educated, and are experiencing more life time achievements (Hodapp, 2007). The life expectancy for an individual with DS is now close to 60 years, in the 1970s it was less than 30 years (NADS, 2011). This life span change brings a whole new set of demographics into view as the number of people with disabilities living at home, as opposed to living in an institutional setting, is expected to increase approximately three fold in the next 20 years (Hodapp, 2007).

Within the more recent disability literature appears the term “Down syndrome advantage,” implying a somewhat lesser impact from the disability of

DS than other developmental disorders, yet there are insufficient data to fully understand its source or the long term outcomes for members of these families (Ricci & Hodapp, 2003; Stoneman, 2007). Between 21 and 46% of fathers describe their children with DS with terms such as happy, cheerful, loveable, and social. Overall, parents of children with DS see their children as having positive personality traits and few maladaptive behaviors; they therefore experience less stress than parents of children with other forms of intellectual disability (Ricci & Hodapp, 2003). This might help to explain some of the so called “Down syndrome advantage.”

The long research history of DS belies its depth. We have learned that families with members who have DS have slightly better coping scores than families with other disorders, yet mostly there are large gaps in knowledge and understanding of these families’ experiences at all levels (Hodapp, 2007). Although the amount of research has increased, we still do not have extensive research that is specifically focused on the various effects or benefits of having a family member with DS (Hodapp, 2007).

Fathering. Fathering is the term used to describe the variety of roles, duties, and responsibilities that men are expected to perform in their relationships with their children (Bachrach & Sonenstein, 1998). Social and behavioral outcomes for children improve when they have engaged fathers (Sarkadi, Kristiansson, Oberklaid, & Bremberg, 2007). Overall, fathers provide a unique contribution to their children’s development. Even though they behave differently than mothers, fathers are able to be just as sensitive and

caring with their newborn infants (Parke & Buriel, 2006; Park, Leidy, Schofield, Miller, & Morris, 2008). Father-child interactions are usually more playful than mother-child interactions and this physical play has been found to promote intellectual and social development in their children (Clark-Stewart, 1978; Lamb, 2000).

The concept of generative fathering advocated by Hawkins and Dollahite (1997) attempts to look at fathering as the work fathers do, rather than a social role they play. Good fathering is generative because it meets Erikson's developmental criteria of "widening concern for what has been generated by love, necessity, or accident; it overcomes the ambivalence adhering to irreversible obligation" (Erikson, Erikson, & Kivnick, 1986, p. 37, cited in Hawkins & Dollahite, 1997). The element of irreversible obligation is particularly salient to this study because DS is a lifelong, persistent, untreatable and irreversible condition.

Fathering can be described as a set of dynamic, complex, developing relationships between fathers and children which take place in the context of a set of equally dynamic relationships between couples and the others that constitute the family system. Of course, the complexity of context continues to expand and convolute outward into a developing system of culture around all of the interactive roles in relationships (Hawkins & Dollahite, 1997). From a developmental perspective, an internal desire for generativity can be a starting point for examining good fathering as good fathering is not just a role to play, but is envisioned by Hawkins and Dollahite as at the center of men's lives.

Therefore, generative ingenuity is needed when doing fatherwork with children with disabilities in order to respond appropriately to their needs. The challenge facing fathers of children with DS is meeting the “non-normative” needs of the child. The special needs of the child may require that a father be especially creative in finding ways to meet the challenges presented (Brotherson & Dollahite, 1997).

Studying fathering in general is challenging, and even more so when the additional factors of a special needs child and the associated ambiguous loss issues are included. Hornby (1994) documents that there is a wide range of effects on fathers who have a child with special needs, including depression, a deep concern for their child’s future, financial concerns, and an increased pessimism about the future. Never the less, this study attempts to address the call for a non-deficit lens in seeking to learn about the experiences of this sample of fathers. In this study, a focus on hope, satisfaction, and coping of fathers will also include examining the relational context in terms of marital satisfaction for this sample.

Marriage roles. Scholars have highlighted the importance of the mother-father relationship for children’s well being and include relationship work in their efforts to better understand fathering, as it contributes to the development of both fathers and children (Hawkins & Palkovitz, 1999; Amato, 1998). It is the family unit that provides the structural foundation of intimacy that leads to an adult’s generative care behaviors, particularly for men (Doherty, 1997). Thus the mother-father relationship becomes a critical

component of the father-child relationship. Economic, social, and emotional supports from two generative, responsible parents provide the most sound foundation for all children to grow and develop (Brotherson & Dollahite, 1997).

The literature indicates that the presence of a child with disabilities has a negative impact on marriages, however this effect was less pronounced than expected (Risdal & Singer, 2004). Hornby (1994) found that marital satisfaction was not found to be significantly different in groups with and without children with DS. In fact, the divorce rate among couples with a child with disabilities is only about 6% higher than among couples with a typically developing child. Hodapp (2007) reported that studies by Carr (1988), Urbano and Hodapp (2007), and Cunningham (1996) showed about an equal likelihood of divorce in families of children with or without DS. Ultimately, the data are mixed but not as problematic as might be assumed.

Work & family interface. One must look at all aspects of the social context to fully understand the fathering experience. In the current cultural context there are now greater demands on fathers to participate in domestic work as well as the expectation to “be there” for their family (Roy, 2004). Yet, the worker/breadwinner element of a father’s identity has undergone changes over the last 30 years. While the concept of the man as the breadwinner of a family has been in decline, there has also been an increase in the awareness of financial risk in the current economy (Kelan, 2008). This increased risk has contributed to young couples’ decisions to delay starting families, which in turn raises the risk of giving birth to a special needs child (Kelan, 2008; NADS,

2010). This economic risk also impacts how couples perceive the breadwinner role and how they make decisions about filling it (Bernard, 1981; Kelan, 2008).

As women have entered the work force, the need for men to participate more on the domestic front has increased. For families with a member who has special needs, the increased demands at home also increase the need for the husband/father to help more in meeting those needs. Some men have embraced the role of involved father, striving for an equal parenting role and more egalitarian domestic participation. Equal parenting encompasses the whole range of emotional and physical activities of child rearing (Gerson, 1993).

Although men still lag behind in engaging in domestic work, across the literature on work and family, parenting, family relations, and marriage, research and information on contemporary families shows that patterns of gendered behaviors are being performed in increasingly egalitarian ways (Daly & Palkovitz, 2004; Gerson, 1993; Hawkins & Dollahite, 1997; Roy, 2004). Men are facing new pressures and increased expectations for their participation in both fatherwork and domestic work, especially for men whose wives work for pay.

Fathers' concerns that have been identified focus on financial costs for caring for the disabled child and the child's influence on the family as a whole (Hodapp, 2007). The anticipation of increased family and domestic commitments conflicts with men's more traditional breadwinner expectations. Faced with the ambiguous loss of raising a child with special needs, a father may choose to embrace the breadwinner role to justify his absence from the

domestic front with concern for the increased demands that a child's disability can place on the family finances. These concerns could be compounded by anxiety about providing adequate funds to support the child after the father's death. Conversely, a father may embrace a more involved role at home so that he could participate in meeting the increased needs of his child. There is currently a void in the literature as to this trajectory for fathers of children with DS and how they navigate it. In slow economic times, fears about challenging these constraints intensify as fathers take on the traditional worries of how to feed their family while also trying to meet increased expectations for their involvement at home (Roy, 2004).

Variables relevant to understanding the intersections between men's roles in fathering, marriage, and the work-family interface within special needs families include hope, satisfaction, and coping. These constructs are explored further in the following section.

Constructs and Framework of the Study

Hope. Hope, the belief in a positive outcome despite evolving circumstances, influences how individuals adapt (Herth, 1992). The subject of hope has long been pondered, from the mythology of Pandora to the existential writings of the 20th century (Vailliot, 1970). Hope is neither optimism nor desire, but rather that intangible persistence in the face of trial to simply be more. As such, the presence of hope influences a person's response to despair. Thus hope is "a multi-dimensional dynamic life force characterized by a confident yet uncertain expectation of achieving good, which to the hoping person, is

realistically possible and personally significant” (Dufault & Martocchio, 1985, p. 380).

Fathers with high hope are expected to be able to cope with having a child with special needs in more positive ways. Since hope sustains a person through difficult circumstances, it may be a factor for men to function effectively in life and as fathers. As such it is a useful construct within a salutogenic model. Given that DS is not a condition that can be treated or cured, the presence of hope may take shape in ways that are useful for understanding the experiences of fathers of children with DS.

Life and marital satisfaction. Satisfaction with life is a global evaluation related to a person’s assessment of their life compared with their own personal concepts and standards. The measurement of satisfaction in the current study is not from an externally imposed definition of a construct, but rather a personal judgment (Diener, Emmons, Larsen, & Griffin, 1985) and thus reflects a participant’s personal evaluation of his or her quality of life. Despite many life stressors, there are parents of children with special needs who report that they are satisfied with their life, and they see their lives as both challenging and satisfying (Asberg et al., 2007).

Attempting to understand satisfaction in the marital relationship is a primary objective in both the relationship and the marital treatment literature. Marital satisfaction is a reflection of one’s attitude toward the marriage and the marriage partner (Bradbury, Fincham, & Beach, 2000). Studies of marital satisfaction have led to a better understanding of both how couples respond to

difficulty and the buffering effects that appear to lead to their resilience in the face of traumatic events (Bradbury et al., 2000). It is relevant to this study because marital quality may impact a father's level of involvement with his children (Cowan & Cowan, 2000; Mehall, Spinrad, Eisenberg, & Gaertner, 2009). A better understanding of marital satisfaction is also useful in this study, as it has been found to be related to coping (Bowman, 1990).

Coping. Coping is generally seen as a means of activating strategies to reduce a stress burden. Folkman and Lazarus (1988) describe coping as taking direct action to affect the source of stress and palliative actions to affect the emotional response to stress. When individuals are better able to cope with difficulties they are more likely to activate planned, positive strategies that lead to a greater sense of mastery and more favorable outcomes (Folkman & Lazarus, 1988; Minnes, Graffi, Nolte, Carlson, & Harrick, 2000).

Parents of children with DS encounter a variety of challenges associated with raising their children (e.g. developmental, medical, educational) and encounter them with more frequency than parents of typically developing children. Coping with their child's condition, understanding what developmental limitations exist, providing or finding providers for specialized care (e.g. occupational therapy, physical therapy, speech therapy), locating community resources and support, and planning for the future are common demands described by parents of children with special needs (Flaherty & Masters Glidden, 2000; Glidden et al., 2006). Since greater demands are placed upon family resources when there is a family member with disabilities, higher

stress levels are found, but those stress levels can be lessened by perceived social support and its contribution to coping strategies (Asberg, Vogel, & Bowers, 2007).

How a family responds to stress and manages available resources can be seen in the coping strategies they activate (McCubbin & Thompson, 1991). Coping strategies include such things as activation of social support networks, which include extended family, friends, and neighbors, and appraisal strategies such as approach to problem solving, reframing, and meaning making (McCubbin & Thompson, 1991). Families who are able to utilize positive coping strategies will better adapt to the stressors involved in raising a child with a disability (Troy, Connolly, & Novak, 2007).

Families with members diagnosed with mental disabilities exhibit coping strategies and behaviors when they are able to invoke protective mechanisms with which to address adversities. For instance, one parent described receiving the diagnosis of DS for her son by saying, “God gave us this gift. A gift to help our family become more loving and caring to each other and those around us. Our little boy with DS is the best gift I could have ever gotten” (Springer & Goff, 2010). This is an example of ‘reframing’, a coping strategy that can make an important contribution to stress reduction (Minnes et al., 2000; McCubbin & Thompson, 1991).

Theoretical foundations. Often as research was conducted to better understand the experiences of families with children who have special needs, the dark lens of the deficit model set the tone for the work and the findings.

Some family scholars purport that a primary purpose of family is to promote the health and optimal functioning of its members and that perhaps a focus on positive functioning is a more appropriate framework in which to do that (Grzyvacz & Ganong, 2009). They advocate using Antonovsky's (1979) salutogenic model, which looks at the health and well being factors that contribute to viable and effective families.

Snarey (1997) posits that the question, "Am I a good father?" is the critical question for a man in determining the generativity of his life and that to answer that question requires a more positive paradigm. Hawkins and Dollahite (1997) also call for a non-deficit model when studying, researching, and analyzing fathers and their relationships with mothers, partners, and children. A deficit model asks, "what is wrong, deficient, missing, in this situation?" A non-deficit model explores what is working; what contributes to that success; what constraints interfere with that success; and, what needs are being met and how. Thus a non-deficit model appears to be the most appropriate model for investigating the resiliency of families, especially with regard to this group of fathers.

The calls for non-deficit models of research still look at individual factors. By using the theory of ambiguous loss, this study begins by identifying the source of stress not as the presence of DS, or some inadequacy of the father, but rather as the presence of the ambiguity of the situation.

Ambiguous loss. The challenges to studying fathering are huge, complex, and lack a theory that is all encompassing and integrative (Palkovitz,

2007). Perhaps in the area of research related to the study of DS, and the families who live with it in their midst, the theory of ambiguous loss can provide the framework for a non-deficit lens to uncover relevant information that can serve to support these families.

The theory of ambiguous loss is a mid-level theory which has been in development for the last 30 years. Boss' body of work has provided basic constructs for both research and practice to examine the many issues which can arise around boundary ambiguity, role ambiguity, identity ambiguity, and ambiguous loss (1999). The theory of ambiguous loss provides a framework for examining the events of life that leave people in a state of limbo, or that are not clearly defined. The core tenets of the theory provide a construct in which to examine uncertain situations that leave one stuck in a state of unresolved coping and grieving. The goal of the ambiguous loss construct is to provide support for sustained hope and resilience in the face of ambiguous loss and the associated uncertainty over the identities of those involved (Boss, 1993, 1999, 2006, 2007).

Families have described ambiguous loss as a trauma that goes on indefinitely, during which they "alternate between hope and hopelessness" (Boss, 1999, p. 24). Ambiguity occurs when someone is physically present, but psychologically absent, as when a spouse has Alzheimer's disease (Boss, 1993), or when someone is psychologically present, but physically absent, as would be experienced when a family member is on a military deployment (Huebner, Mancini, Wilcox, Grass, & Grass, 2007). A diagnosis of DS can have a similar

effect (Springer & Goff, 2010). Like an ambiguous loss, a diagnosis of DS represents a long term, permanent change in life's trajectory, with many unknown elements. Interactions with a child with DS have been described as emotionally engaging despite mild to severe mental impairments (Ricci & Hodapp, 2003). A child with DS could be perceived by some as physically present but psychologically absent (to varying degrees) due to their impaired physical and mental abilities (Boss, 2006; O'Brien, 2007).

People have an innate desire for life to be consistent and predictable. The theory of ambiguous loss was developed as a way to frame the disparity some may experience between their cognitive construction of family and the reality with which they live (Boss, 1999). The theory provides a means for explicitly labeling and describing the phenomenon of learning that your child has DS. A child with DS is physically present, but due to their mental and physical disabilities parents may find their new child to seem psychologically less capable than a typically developing child. The theory of ambiguous loss provides a paradigm for recognizing and addressing the ambiguity in this circumstance (Boss, 1999).

The ambiguous loss framework also gives families a way to describe the confusion and sense of immobilization that may grip them in this circumstance. The uncertainty that accompanies a diagnosis of DS can make it difficult for some families to discern the roles and rules of the relationships within the family unit. Without any of the rituals that symbolize a loss, there is little validation for the feelings they may experience. Extended family and

friends may also struggle with how to show compassion or offer support.

Finally, the experience of ambiguous loss can be both physically and emotionally exhausting for those in its midst (Boss, 1999).

The ambiguity that stems from a diagnosis of DS could exist on two levels. One is the uncertainty of the level of impairment which leaves future functioning as an unknown factor. Second, the theory provides a framework for the family to grieve the loss of the more typical child and life path they may have been anticipating. The uncertainty that accompanies this ambiguity can be paralyzing for some, as it complicates both the loss and the processes of mourning (Boss, 1999). As this continues, conflict tends to enter into the strained relationships within the family as well as with service providers (Boss, 1999).

Although many studies and reviews (see *Family Relations*, April 2007) have utilized Boss' constructs, more research related to families who have members with special needs could expand the body of work into an area that begs for attention. Families with a special needs loved one constitute a unique demographic for research with this theory. Boss (1999) outlines treatment guidelines and therapeutic interventions that could operationalize appropriate variables to address a deeper understanding of ambiguous loss experiences as well as improved efficacy of treatment. As families manage their lives with DS they may realize their experience will vacillate between a sense of control and one of helplessness. Their attitudes of hope and satisfaction, as well as their methods of coping, speak to how they manage during the emotional roller

coaster that is now a central part of their lives. Boss (1999) further posits that hopefulness plays a useful role when coping with ambiguity.

Research Questions

The current study was designed to address three research questions.

1. Do fathers of children with DS show different patterns of hope and satisfaction?
2. If so, do those hope and satisfaction groups differ in the coping behaviors they report using when learning of the diagnosis?
3. Finally, what are the fathers saying that helps us to better understand the heterogeneity of this sample of fathers?

Chapter III

Methods

To address the need for a non-deficit model that studies the experiences of fathers of children with DS a person centered mixed method, descriptive, exploratory design was used. Exploratory research investigates without explicit expectation - to capture meaning (Schutt, 2004). A critical aspect of understanding development is to focus on the unique pathways individuals take to grow and change over time (Schaffer, 2006). The different ways fathers experience, respond to, cope with, and progress in the wake of having a child with a developmental disability are not well understood (Hodapp, 2007).

A person centered approach was taken in this study to highlight the expectation that, although different fathers of children who have DS have some similar experiences; they are more different from each other than they are the same (Hodapp, 2007). A quantitative person centered cluster analysis can provide a non-deficit model, as it can address the need for understanding individual experience, potentially revealing many pathways that are positive for fathers. At the same time it can also provide much needed data that support a more thorough understanding of coping within this sample. Variable-centered analyses focus on overall group averages, which may obscure differences among meaningful groups of participants within a sample (Bergman, 2000). There are tools to measure heterogeneity within a sample, and they have been developed in person centered approaches (Bergman & Trost, 2006; Lange, Senior, Iverson & Chelune, 2002). Cluster analysis is exploratory and sorts

individuals into groups (Bergman & Trost, 2006, Lange et al., 2002). A follow up variable centered analysis was then used to validate the clusters and determine whether these groups demonstrated differences in coping behaviors (Lange et al., 2002).

A weakness of this approach is that although the person oriented methodology attempts to describe and understand the individual in a sample, it cannot express the specifics of individual fathers' lived experiences. No amount of statistical manipulation can fully capture a truly clear picture of one person's life. Qualitative research methods provide an avenue to explore the potential for rich, thick descriptions of daily life for fathers of children with DS. A qualitative study would be well suited to capture the meaning-making that a father employs when he has a child with a disability. Each individual makes his or her own specific meaning of the symbols and events of their life through the varied lenses of their culture, their gender, their education, and their ethnicity (Denzin & Lincoln, 1998). From the qualitative research, a better understanding began to emerge that provided a better understanding of pathways to successful coping strategies for some fathers. The limited amount of research in this area begs for qualitative as well as quantitative findings. A qualitative directed content analysis was used to fill this void.

Sample

Sampling is a core issue of research in the social sciences (Schutt, 2004). How a sample for a study is chosen determines how a study can be interpreted and utilized (Schutt, 2004). Research in the area of fatherhood and disabilities

requires a unique sample that may warrant methodological study in and of itself as men are typically under-represented in family studies research (Sandelowski, 1995). Volunteering to participate in research is seen as a non-random event that is influenced by personality attributes, experience in a particular situation, or some motivation (Rosnow & Rosenthal, 1976; Schutt, 2004). Since mothers are often primary caregivers of children with disabilities (Hodapp, 2007) and may act as gatekeepers (Fagan & Barnett, 1995), fathers may or may not have an opportunity to interact with or respond to a call for research, and those who do may or may not accurately represent all fathers of children with a developmental disability. The most feasible way to reach fathers of children with a developmental disability is through organizations or services offered to them that are specific to their needs. This means of purposive, convenience sampling can only produce results that are specific to the sample being studied; thus its generalizability is limited (Schutt, 2004).

For this study, participants were recruited through local and national groups, including the National Down Syndrome Congress (NDSC; research webpage and national newsletter), Down Syndrome Guild of Greater Kansas City (webpage and newsletter), Band of Angels, and Council for Exceptional Children. In addition, the NDSC forwarded information to contacts at affiliate organizations nationwide for distribution of the study information through their local membership listservs. The research procedure was approved by both the Texas Tech University Institutional Review Board (IRB) and the Kansas State University IRB.

Materials for recruitment included a survey web link and online information about the study. The survey was available for interested individuals to access and complete online. As part of the process, participants were invited to include contact information for further follow-up interviews. Of the 487 participants, only 62 identified themselves as male and fathers of a child with DS. These men ranged in age from 28 to 66. The sample was 93% European American-white. Amongst these men 84% were married, the length of marriage ranged from 1 to 41 years. Only 2% identified as divorced, and 7% identified as remarried. Most couples were dual earners with a college education and 60% have an income level above \$90,000 annually. These fathers reported having from one to five children, 84% had three or less children (natural, step, or adopted). Most (70%) identified themselves as Christian.

Measures

Based on anecdotal reports about the DS parenting experience, the concepts of hope, satisfaction, and coping were of interest to the principal investigators. Four of the measures from the original survey were used in this study. Those measures include the Herth Hope Index (HHI) (Herth, 1992), the Couples Satisfaction Index-4 (CSI-4) (Funk & Rogge, 2007), the Satisfaction with Life Scales (SWLS) (Diener et al., Emmond, Larson, & Griffin, 1985), and the F-COPES Scale (McCubbin & Thompson, 1991). Each is summarized below.

Herth Hope Index. Hope has been conceptualized in various ways.

Measures used for this study examine three dimensions of hope for the development of the Herth Hope Index (HHI) (Herth, 1991). First is a person's opinion that positive outcomes are realistic and possible. Second is that a person has a sense of purpose and direction for successfully achieving a goal that will influence the desired outcome, and third the individual has the contextual relationships to support that goal for that desired outcome.

The HHI is based on the longer and more in depth Herth Hope Scale (HHS) and was designed for clinical use. Due to its shorter length, (12 items versus 30 items), participants appear to be more willing to complete the measure and fatigue has less influence on their responses (Herth, 1992). Questions include: *I have a positive outlook toward life* and *I feel scared about my future*. The HHI's 12 items are answered in a four point Likert-type format with a score of 1 meaning *strongly disagree* and a score of 4 meaning *strongly agree*. All negative items were reversed scored. Total scores can range from 12 to 48. A higher score indicates a higher level of hope (Herth, 1992).

The psychometric evaluations for the HHI were conducted with a heterogeneous population. The Cronbach coefficient alpha was 0.97, and the test-retest reliability was 0.91. The HHI has been shown to have both face and content validity. It was also shown to have concurrent criterion related validity ranging from 0.81 to 0.92, assessed by correlating the HHI with the following three measures: the HHS ($r = .92$), the Existential Well-Being Scale ($r = .84$) and the Nowotny Hope Scale ($r = .81$) (Herth, 1992). The positive correlation of 0.84

with a theoretically related measure is evidence of construct validity. Construct validity for the HHI was further confirmed with the original HHS sub-scales. All items of the HHI significantly loaded on the three HHS sub-scales of temporality and future, positive readiness and expectancy, and interconnectedness. Alpha coefficients ranged from 0.78 to 0.86. Divergent validity was also established with a negative correlation (-0.73) to hopelessness (Herth, 1992).

Couples Satisfaction Index. The Couples Satisfaction Index (CSI) was developed to provide a more precise relational satisfaction measure. By design it specifically limits confounding variance with communication constructs, and is able to identify meaningful effects in smaller samples (Funk & Rogge, 2007). For the current study the CSI(4) was used. The CSI(4) consists of items number 1, 12, 19, and 22 of the full Couples Satisfaction Index. Items include, *How rewarding is your relationship with your partner?* This question is answered with a 6 point Likert-type scale with a score of 1 meaning *not at all* and a score of 6 meaning *completely*. The CSI correlates strongly with both the widely used Dyadic Adjustment Scale (DAS) and the Ineffective Arguing Inventory, 0.87 and 0.79, respectively (Kurdek, 1994). Total scores range from 4 to 24, with more satisfaction associated with higher scores. The CSI has a distress cut-off score of 13.5, which correlates with the distress criterion of the DAS (Funk & Rogge, 2007).

Satisfaction with Life Scale . This scale is a subjective assessment of life satisfaction that reflects an individual's own judgment of their personal

quality of life as a cognitive-judgmental process. The Satisfaction with Life Scale (SWLS) is a 5-item Likert type scale asking for evaluation of such statements as: *In most ways my life is close to my ideal* and *I am satisfied with my life*. Responses vary from 1- meaning *strongly disagree*, to 7- meaning *strongly agree*. This scale was normed with both a college student sample and an elderly citizen sample with a mean age of 75 years. The internal consistency is very good, $\alpha = .87$. It also appears to be quite stable with a test-retest correlation of 0.82 over a two-month period (Diener, et al., 1985). The measure also has good reports of validity (Diener, et al., 1985). Total scores range from 7 to 35 with more satisfaction associated with higher scores. Diener (2006) has published a clinical evaluation of the scores for this scale.

The F-COPES Scale. The F-COPES Scale is a 30 item measure, developed by McCubbin, Olson, and Larsen to examine how families cope (McCubbin & Thompson, 1991). The stem question for this measure was: *“When our family learned about our child’s diagnosis with Down syndrome, we responded by: _____.”* The F-COPES is scored on a 5 point Likert type scale with 1- meaning *strongly disagree* and 5- meaning *strongly agree*. Some items in the scale were reversed scored.

The F-COPES measure assesses various ways that are used to address family stressors such as: acquiring social support (*sharing our difficulties with relatives*); reframing (*knowing that we have the strength within our own family to solve our problems*); seeking spiritual support (*attending church services*); mobilizing family to acquire and accept help (*seeking information and advice*

from the family doctor), and passive appraisal (*watching television*). The scale has been evaluated with thousands of participants. Reliability of the instrument is excellent, as it has very good internal consistency ($\alpha = .86$) and a four-week test-retest has stability, with a correlation of .81. The scale also has very good factorial validity and good concurrent validity. A total score for the scale can range from 30 to 150. Higher total scores on this measure are associated with more adaptive family behaviors and problem solving strategies in difficult circumstances (McCubbin & Thompson, 1991).

Furthermore, the online survey also had nine open-ended questions. Three of those questions were examined qualitatively (see Appendix for entire survey) and are listed in the following section.

Research Design

Analysis. The first goal of the current study was to identify subgroups of fathers within the sample based on their hope and satisfaction attitudes and beliefs. A person-oriented research approach attempts to understand individuals within the context of their own person-environment system (Bergman & Trost, 2006). This technique attempts to take into consideration the many different components that affect individual development and the behaviors that follow. For this study, the components focused on hope, satisfaction, and coping will reflect beliefs and behaviors that may reveal adaptive coping in a family environment. A qualitative directed content analysis follows to give better understanding of the identified clusters.

Cluster analysis procedures. Composite variables created for each of the contributing scales were used in clustering. To control for variations in scaling between measures and to maximize the cluster solutions, all scale scores were standardized using z-scores. Since the purpose of cluster analysis is to find profile patterns, a z-score transformation is appropriate (Lange et.al., 2002).

As recommended by Lange et al. (2002) a two step cluster analysis was conducted. First, Ward's Method of hierarchical clustering was used in SPSS to identify the best and most meaningful number of clusters of hope and satisfaction among the fathers in the sample. A visual inspection of the graphical output guided selection of the number of clusters. A *k*-means cluster analysis was then used to determine cluster membership. Hope and satisfaction clusters were based on their responses to the HHI, CSI, and SWLS scales. The cluster analysis was then validated with a MANOVA on the hope and satisfaction variables by cluster. **Internal validity of the cluster solution was established with a mixed MANOVA within and between clusters to confirm group differences (Lange, et al., 2002).**

Variable centered examination of group differences. A variable centered follow-up examined whether there were group differences by cluster on coping behaviors. An ANOVA was performed using the F-COPE composite score as the dependent variable. Cluster membership, as identified from the cluster analysis, was the independent variable. From this analysis, patterns

that provided a more thorough description of the fathers in the sample in relation to their coping behaviors were derived.

Directed content analysis. While quantitative research allows us to seek broad sweeps and generalizations of human life, sometimes we are allowed to glimpse the unseeable. Qualitative research provides a window for a better understanding of how individuals give meaning to their behaviors (Richards & Morse, 2007). Qualitative methods allow for more individualized study of the stories that tell more about fathers' lived experience as fathers of children with DS. One advantage of qualitative research is that by asking fathers for narratives, they are then free to describe their life in terms that are meaningful to them, as opposed to the researcher choosing instruments that frame the father's responses (Baker, Wuest, & Stern, 1992; Weaver, Wuest, & Ciliska, 2005). Is there a process by which fathers organize their coping behaviors when they have a child with a disability? A qualitative approach may be able to reveal what perspective fathers find the most useful as they fulfill their roles as fathers of children with DS.

For this aspect of the study, a directed content analysis approach was used with the text data available from the open ended questions in the survey. A directed content analysis is a qualitative research approach of text data that is guided by relevant research findings and can provide further understanding of the phenomenon being studied (Hsieh & Shannon, 2005). The clusters are intended to provide the themes or patterns for subjectively exploring a richer understanding of who these fathers are. Using the clusters found in the

quantitative analysis, this naturalistic paradigm helps to reveal emic accounts that can provide a clearer understanding of the fathers who comprise each cluster. The directed approach to content analysis has the potential to validate and conceptually expand our understanding of the inherent clusters in the data set (Hsieh & Shannon, 2005).

The text data are from the same sample of fathers and were collected in the same online survey that was used for the cluster analysis. The open ended questions used for the qualitative directed content analysis were:

1. Describe how you responded to your child's diagnosis compared to your spouse/partner.
 - What similarities or differences were there between how you and your spouse/partner responded to the *initial* diagnosis?
 - What do you see as the causes of those similarities or differences in your responses?
 - What differences are there *currently* in how you and your spouse/partner respond to your child?
2. Describe your *current* attitude about your child's diagnosis with Down syndrome. If it is helpful, describe your rating on a scale of 1 (poor) to 10 (excellent).
3. How have you been most impacted personally by your child's diagnosis with Down syndrome?

The sample size of approximately 50 has been identified as adequate for obtaining fuller qualitative descriptions (Sandelowski, 1995). Qualitative coding

began with the parameters found in the descriptions of the various clusters as recommended by Hsieh & Shannon (2005). Any categories found in the text outside of those defined by the cluster analysis were identified and kept for further analysis. These categories are intended to either support the findings of the cluster analysis or offer another point of view that will need to be explored in relation to these fathers of children with DS.

Hsieh & Shannon (2005) delineate three limitations to directed content analysis. The first is a concern regarding researcher bias due to the informed perspective driving the use of this type of analysis. In this study, the purpose of the directed content analysis was to more explicitly describe the clusters, thus the possibility of this bias is actually beneficial to the goal of describing the fathers who comprise the cluster. Second, they are concerned that cues may exist in the wording of the qualitative questions that would influence the answers from the participants. Since the principal investigators did not initially envision an exploration of the data using cluster analysis or directed content analysis, the open ended questions were not developed with the specific conceptualizations of hope and satisfaction in mind. However, it must also be kept in mind that since the survey data on all three concepts being used for analysis preceded the open ended questions, certain conceptualizations may be triggered in participants' thinking prior to answering the questions. Hsieh & Shannon's (2005) final concern is related to objectivity being limited by the preconceived concepts under investigation. For this study, objectivity was addressed by an independent audit and confirmation by a

colleague.

Just as qualitative research will struggle to tell the many varied stories of a large group, quantitative research struggles to tell the story of individuals when the only resource is the aggregation of variables. By using a person centered quantitative analysis and a directed qualitative content analysis, this study can contribute to a better understanding of this sample of fathers.

Chapter 4

Results

The results will be presented in four sections. The first addresses the preparation of the data for the person centered analysis. The next section reports the findings of the cluster analysis which was utilized to answer the first research question, investigating father's patterns of hope and satisfaction. This section includes descriptions of the clusters found in the text data via the qualitative directed content analysis, as probed in the last research question. The variable centered findings which address the second research question regarding coping strategies and behaviors will be reported in the next section. It also includes the directed content analysis concerning coping. Last, an analysis of the results within the framework of the theory of ambiguous loss will be presented to further understand the heterogeneity of this sample of fathers.

Data Cleaning

Prior to analysis, data accuracy, missing values, and violations of standard assumptions of multivariate analysis were assessed. Eight fathers were deleted from the analysis because they did not complete all of the scales used in the analysis. Five of those fathers were divorced and not in a dating relationship, and were hence ineligible to answer the questions related to couple satisfaction. Fifty fathers remained in the study, which is the minimum number for cluster analyses recommended by Lange et al. (2002).

Another consideration was a small amount of missing data. It was determined that less than 5% of the total data was missing for the 50 participants in the study. To determine if the missing data was missing completely at random (MCAR), missing at random (MAR), or missing not at random (MNAR), a dummy variable was created. The eight missing data points were responses to survey questions and were contained within only four subjects. These four subjects were given a score of 0 (zero), all others received a score of 1. Tests of mean differences (ANOVA and t-test) were used to determine if the missing data group was different than the other group. Since there were no significant differences in regard to the missed questions, how to handle the missing data was not critical (Tabachnick & Fidell, 2007). The missing data were characterized as MCAR. The SPSS function *Transform Missing Value* was used and a series mean calculation was employed to estimate values for the 8 data points. While this is the least recommended methodology, it was appropriate because only 0.27% of the data was MCAR.

The cluster variables were examined to confirm that they were measuring different constructs in this data set. Correlations between the constructs were run and they were not highly correlated (see Table 4.1).

Table 4.1: *Correlations of HHI, CSI, SWSL*

	HHI	CSI	SWSL
HHI	-		
CSI	.27	-	
SWSL	.61***	.51***	-

Note. *** $p < .001$

To control for differences in scaling between variables and to maximize the clustering solutions, three latent class variables were created as a composite score for each scale to be used in the clustering technique. Since the scales had significant skewness, a square root transformation was used. The variables were then transformed into z -scores because each scale was different. Since the purpose of the cluster analysis was to find profile patterns, a z -score transformation was appropriate (Lange et al., 2002). Higher scores on each of the three scales indicated a higher level of hope or satisfaction.

Cluster Analysis

A cluster analysis technique was used to explore and describe perceptions of hope and satisfaction among fathers of children with DS. Hope and satisfaction clusters were established as a function of responses to three measurement scales, the Hearth Hope Index (HHI) (Hearth, 1992), the Couples Satisfaction Index (CSI) (Funk & Rogge, 2007), and the Satisfaction with Life Scale (SWLS) (Diener et al., 1985). This procedure was done using SPSS (SPSS, V.18) and was comprised of two steps. First a hierarchical technique, Ward's method, was used to determine the appropriate number of clusters. Three clusters were identified in the resulting dendrogram. This finding was confirmed by an independent examiner as recommended by Lange et al. (2002). A k -means analysis was then performed using the number of clusters identified in the hierarchical analysis. Evaluation of the hierarchical and k -means cluster analysis supported a three cluster solution that was used in further analysis.

Subject assignment in each cluster was over 5% as recommended by Lange et al. (2002). Based on their profiles, the clusters are labeled: Cluster 1 - *Hoping* (n=13); Cluster 2 - *Connecting* (n=23); Cluster 3 - *Thriving* (n=14).

The cluster analysis was validated with a MANOVA to examine group differences on the hope and satisfaction variables by clusters. The MANOVA was significant ($F(6, 90) = 24.44, p < .001, \eta^2 = .62$), confirming that the three groups identified by cluster analysis were different on the hope and satisfaction variables. At the univariate level, significant main effects of clusters were present for all three dependent variables: *HHI*, $F(2, 47) = 34.72, p < .001, \eta^2 = .60$; *CSI*, $F(2, 47) = 20.51, p < .001, \eta^2 = .51$; and *SWLS*, $F(4, 47) = 36.41, p < .001, \eta^2 = .61$.

Three groups were found to be distinctly different and their names were chosen in accordance with the cluster analysis as well as the directed content analysis. The *Connecting* cluster fell between the *Hoping* cluster and the *Thriving* cluster on all of the three clustering variables of hope and satisfaction. The *Hoping* cluster had the lowest scores on all three variables, and the *Thriving* cluster had the highest scores on all three variables. Although the *Hoping* cluster has the lowest scores of all three clusters on these scales, the mean scores for the cluster are still in the higher range for most of the measures.

Three distinctly different clusters were found in this sample (see Figure 4.1 & Table 4.2). The lowest scoring cluster, *Hoping* (n = 13), also the smallest cluster, had the lowest scores on all three clustering variables. The mean

scores for this cluster were still in the higher range for most of the measures. The highest score for this cluster was on the hope measure. The largest cluster, *Connecting* (n = 23), fell between the other two clusters on all three of the clustering variables of hope and satisfaction. The satisfaction scores for this cluster were higher than the hope score. The third cluster named *Thriving* (n = 14), was the highest scoring cluster on all three clustering variables of hope and satisfaction.

Figure 4.1: *Graph of final cluster solution profiles.*

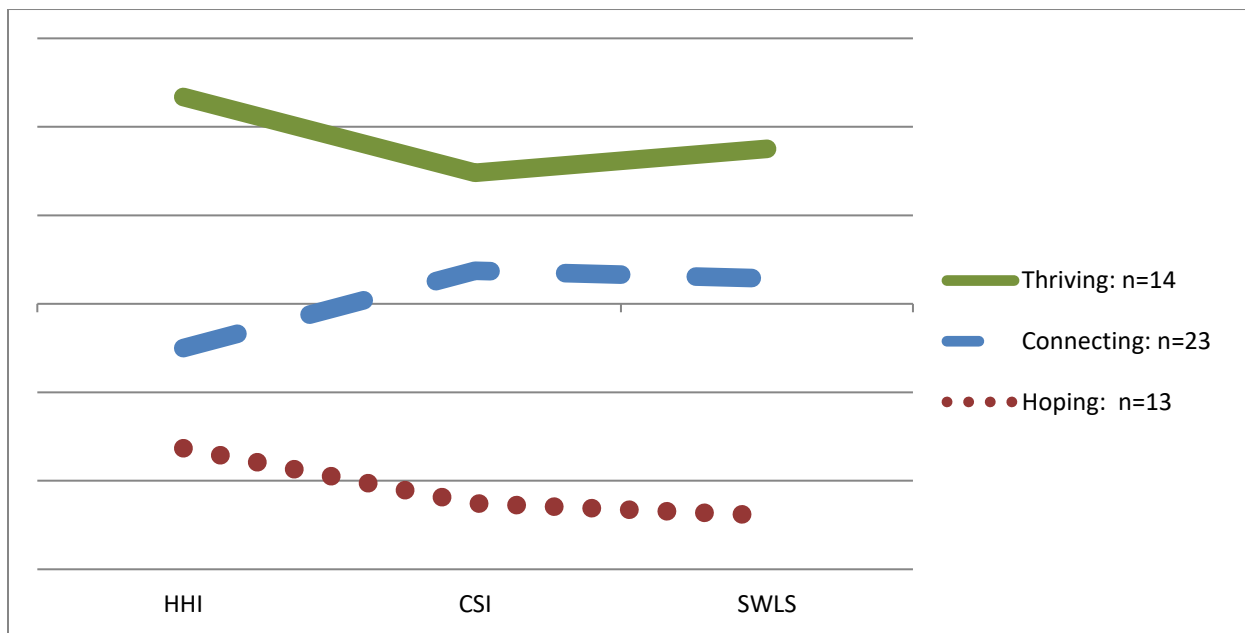


Table 4.2: *Mean scores of cluster variables by cluster*

	<i>Hoping</i> (n = 13)	<i>Connecting</i> (n = 23)	<i>Thriving</i> (n = 14)
HHI	38.0	41.0	46.5
CSI	13.5	19.9	21.6
SWLS	19.5	28.0	31.0

The qualitative content analysis in this study was guided by a structured approach which began with the cluster analyses and used the key aspects of each clustering variable (Hsieh & Shannon, 2005). Three open ended questions concerning initial response to the diagnosis of DS, current attitude, and how fathers perceived themselves as being impacted personally, provided text data which could contain further understanding of the phenomena of interest. Using the concepts behind each measure, the text data were coded for examples of hope, satisfaction, and coping. Text that did not fit into these categories was noted for further examination. The directed content analysis provides an opportunity for a richer understanding of each cluster, in terms of the clustering variables, coping, and the ambiguous loss theory. All three of the open ended questions were examined. The coding scheme was developed from the prior exploration with the clustering techniques and was used to both enrich and refine knowledge and understanding of the lived experiences of these fathers of children with DS. These findings will be used to expand understanding of the clusters and will be embedded in each cluster description.

Cluster Descriptions.

The Hoping cluster. The *Hoping* cluster (n=13) is characterized by scores on all three clustering measures that fall below the other two clusters. The mean scores on the clustering measures for the *CL1* cluster are: HHI (M=38.0, SD=3.92), CSI (M=13.50, SD=4.60) and SWLS (M=19.53, SD=5.01). Although the HHI score for this cluster is the lowest of all the clusters, a score

of 38.0 is still in the top third of the range for the scale. Of all the scaled scores utilized in the clustering, the fathers in this cluster scored highest on this particular scale. The range for scores on this scale is from 12 to 48. A score in this range would still likely represent some expectancy of a positive outcome and a sense of connection to others (Herth, 1991). The CSI mean score of 13.5 is just below half of the possible scores for the scale and is the cut off score for distressed couples. The range of scores for this scale is 4 to 24. This is the lowest CSI score of the three clusters and may reflect how the couples in this cluster are responding to the inherent difficulties of raising a child with a disability. Finally, the SWLS mean score for this cluster was 19.5 which is considered a slightly below average score (Diener, 2006). Scores in this range are reflective of individuals who may have a significant difficulty in their life. Interpretation of this score must include a consideration of how long the individual has been at this level of dissatisfaction. If it is related to a specific occurrence, there is a likelihood that a higher level of satisfaction with life will return, whereas, a chronic level of dissatisfaction is cause for concern (Diener, 2006). This cluster was named *Hoping*, because the profile of the cluster shows that their scores on the HHI are relatively high and reflect a positive attitude, despite lower satisfaction scores. The text data for this cluster provided further support for this conclusion.

This cluster is comprised of 13 fathers ranging in age from 30 to 61, with a mean age of 46. One did not give his age. Most of the respondents were European-American White (84.6%), one is of Asian or Pacific Islander descent,

and one did not respond. Ten of the fathers are married, one is currently separated, one is living with a partner, and one did not respond. The length of marriage for men in this cluster ranged from four years to 41 years ($M=17.68$, $SD=11.47$), and was very evenly distributed across that range. Only two of these fathers (15.4%) indicate more than one marriage. All of these fathers had only one child with DS, and 77% of these fathers had more than one child (2-5 children). The age of the child with DS ranged from two to 25 years old, only half of the children were between 2 and 10 years old ($M=10.25$, $SD=7.7$), and most of them were boys (75%).

The fathers in this cluster all had at least some college, 83% completed college, 67% of them had at least some graduate work, and half (50%) had a Master's or a Doctorate degree. Seventy-five percent of this group was employed full-time, one was employed part-time, and two were unemployed; not due to a disability. The income level for this cluster was quite diverse. Almost 55% of respondents indicated an annual family income in excess of \$90,000, 36.4% reported family income between \$60,000 and \$89,999, and one reported income below \$40,000. As found nationwide (NDSC, 2010), most of these fathers (66.7%) learned of their child's diagnosis with DS after the child was born. National samples consistently report that a majority of parents do not know their child has DS until after the child's birth (Skotko, 2005). Finally, in this sample, 58.3% identified as Christian, one as a Muslim (7.7%), and four (30.8%) claimed no religious preference. The fathers in all three

clusters were relatively similar. For the most part they were married; highly educated; employed; and had a relatively high income level (see Table 4.3).

Table 4.3: *Descriptive Statistics for fathers and children (range in parentheses).*

	Full Sample (<i>N</i> = 50)	<i>Hoping</i> (<i>n</i> = 13)	<i>Connecting</i> (<i>n</i> = 23)	<i>Thriving</i> (<i>n</i> = 14)
Age (years)	49.14 (30-65)	45.75 (30-61)	41.19 (31-60)	43.64 (35-65)
Total # of children	2.46 (1-5)	2.33 (1-5)	2.26 (1-5)	3 (2-5)
Age of child with DS (years)	7.19 (.17-25)	10.25 (2-25)	5.38 (.17-21)	7.48 (.83-21)
Child Gender (%)				
Male	58	69.2	69.6	28.6
Female	32	23.1	26.1	50
Relationship length (years)	14.08 (4-41)	17.68 (4-41)	12.95 (4-26)	12.73 (7-27)
Marital Status (%)				
Married	86	76.9	95.7	78.6
Cohabiting	2	7.7	0	0
Dating	2	0	4.3	0
Separated	2	7.7	0	0
Ethnicity (%)				
White	86	84.6	95.7	71.4
Asian American	2.2	7.7	0	0
Latino/Hispanic	2.2	0	4.3	0

Education Level (%)				
Some College	12	15.4	8.7	14.3
Completed College	28	15.4	34.8	28.6
Some Graduate Work	12	15.4	17.4	0
Master's Degree	24	15.4	26.1	28.6
Doctorate	14	30.8	13	0
Employment (%)				
Full-time	74	69.2	82.6	64.3
Part-time	4	7.7	4.3	0
Unemployed	8	15.4	8.7	0
Retired	4	0	4.3	7.1
Annual Income Level (%)				
< \$59,999	12	7.7	13	14.3
\$60,000-\$89,999	20	30.8	17.4	14.3
> \$90,000	50	46.2	65.2	28.6
Learned of DS Diagnosis (%)				
After birth	60	61.5	69.6	42.9
Early Ultrasound	6	0	4.3	14.3
Amnio	12	15.4	13	7.1
Other	12	15.4	13	7.1

Note: There is some missing data. Thus percentages do not always add up to 100%.

The directed content analysis supported the findings of the somewhat high HHI composite score in this cluster. Furthermore, the theme of hope was pervasive in these narratives. Every member of this cluster had a comment that related to an aspect of hope. Love for their children, as well as participation in groups, activities, and schools are common occurrences. A large number of responses indicated a positive outlook on life, despite the mitigating circumstances, and a sense of direction and goals for life were referenced. There were multiple instances of this group of fathers describing expectations they had for their children with DS and the ways they would push for those expectations to be met.

“I push her more. I pushed her from the bassinet to the crib, from overnight feeding to during the day, from four feedings to three, etc. I’ve worked with her more at home to get her to walk,” said the father of a four year old girl. (Robert age 42, daughter age 4)

“Right now [my son] is 17 and I am really planning and pushing for his independent living outside our home...I want him prepared for the real world and a great job and to continue school.” (Reid unknown age, son 17)

The text responses also told a story about the marriages of the members of this cluster. It provides a richer understanding of this cluster’s CSI score at the distressed level. These men wrote that often they did not have a similar response as their spouse/partner to either the news of their child’s diagnosis or in their approach to raising their child. One father said, “At times our different ways of dealing with things caused issues.” Yet, he follows up that statement by saying, “Over the years our relationship has gotten stronger” (Richard age 32, son age 10). Another father described his experience by saying, “My wife at

the time, I have since remarried, did not want to know anything about it. She was in total denial. She also hated God for doing this to her, then she wanted to place blame.” He went on to say, “...she thought it was totally my fault.”

(Ralph age 46, son age 16) Other fathers say, “We need each other for balanced strength. The times I was weak, [she] was strong and vice versa.” (Reid, no demographics). The stories are of both conflict and resolution over time in their marriage relationships. There is an underlying tenor of acceptance, commitment, and resolution in this cluster; rather than joy and satisfaction.

Diener (2006) expressed concern for SWLS scores in the range found for this cluster, especially if their level of satisfaction is chronic. Since half of the children in this cluster with DS are older (between 8 and 25 years of age) there is reason to consider that this lower level of satisfaction with life is indeed chronic. Several fathers commented on the difficult path of worrying about their child’s future and some discussed their personal levels of depression.

“I worry a lot about the future and how the rest of the world will accept him or not accept him...” (Rod age 35, son age 2).

He’s not now or will ever be, ‘high functioning’. I get depressed often, even though I’ve accepted this role as a parent, and am willing to make the sacrifices needed....I get saddened because we have to take separate vacations with my daughter, so she has somewhat of a normal life with the family...the idea of being stuck in the house [as a stay at home dad], and having limited contact with the outside world because I’ll be taking care of him for the rest of my life, really wears on you (Russ age 56, son age 13).

Connecting cluster. This cluster (n=23) is characterized by scores on all three clustering measures that fall between the other two clusters. The mean

scores on the clustering measures for the *Connecting* cluster are: HHI (M=41.0, SD=3.36), CSI (M=19.9, SD=2.26), and SWLS (M=28.0, SD=2.54). The HHI score of 41.0 is in the top third of the range for the scale. The range for scores on this scale is from 12 to 48. A score in this range would likely represent a persistent expectancy for a positive outcome and a sense of connection to others (Herth, 1992). The CSI mean score of 19.9 is also in the top third of possible scores for the scale and considerably above the distress cut off score of 13.5 (Funk & Rogge, 2007). The range of scores for this scale is 4 to 24. Finally, the SWLS mean score for this cluster was 28.0 and is considered a “high score” (Diener, 2006). Scores in this range are reflective of individuals who like what is going on in their life, and challenges may be part of what brings them a sense of motivation. This score reflects a feeling that “...things are going well” (Diener, 2006, p.2). The mean scores on the hope and satisfaction measures for this cluster reflect an attitude of contentment with life.

This cluster was comprised of 23 fathers ranging in age from 31 to 60, with a mean age of 41. Two fathers did not give their age. Most of the respondents were European-American White (95.7%) and the remaining two fathers were of Latino/Hispanic descent (4.3%). All but one of the fathers was married and the unmarried father was in a dating relationship. The length of marriage for this cluster ranged from four years to 26 years (M=12.95, SD=6.00), and was fairly evenly distributed across that range. Only two of these fathers (21.7%) had been married more than once. Ninety-five percent of these fathers had only one child with DS, one father had two children with DS,

and 75% of these fathers had more than one child (2-5 children). The age of the child with DS ranged from newborn to 21 years old, however 90% of the children were age 11 or under, and most of them (70%) were boys.

As portrayed in Table 4.3, 11 fathers in this cluster had at least some college, 91% completed college, and 56.5% had at least started some graduate work. Almost one-third of this cluster had a Master's or a Doctorate degree. Eighty-two percent of this group was employed full-time and only one was retired. The income level for this cluster was mostly in the upper 20% of U.S. households (U.S. Department of Commerce, 2006). More than half of the respondents reported an annual family income over \$100,000 and almost 70% reported an annual family income in excess of \$90,000. Most of these fathers (69.6%) learned of their child's diagnosis with DS after the child was born. Finally, in this sample, most (82.6%) participants identified as Christian.

The directed content analysis provided support for the findings of the HHI, with a large number of responses that indicated a positive outlook on life. One father said:

“So what if he has DS. That isn't what he is. He is a great kid and my son. DS is just a condition that has to (be) managed just like if he had asthma or a speech impediment. Everything is manageable. Not a big deal. ... We love him and wouldn't change anything.” (Bart age 32, son 21 months)

Another said: “He reminds us of what is good in life.” (Brett age 48, son 6 years)

Examination of the open ended question about responding to the diagnosis of DS revealed that the fathers in this cluster often experienced a

similar response as their spouse/partner. The most repeated expression of satisfaction within the marriage was related to the couple's similar response when they learned of their child's diagnosis. Comments such as; "We responded in very similar ways," or "We were both shocked...we took turns supporting each other...through the various phases of dealing...we looked towards each other for support," were frequent comments found interspersed throughout responses to this question. As with the previous cluster, but to a lesser extent, there were also examples of difficulty, as well as commitment, in the marriage after the diagnosis.

"My wife was highly upset and immediately started blaming and looking at the negative side of everything. ... She was even upset with me for not being mad about the diagnosis." (Brett age 48, son age 6)

"Our marriage is one of two very different people. Yet we were, and have been, united by our love for our son, and our commitment to him. His presence has literally stopped us from fighting on several occasions and strengthened our marriage." (Beau age unknown, son age 5)

Numerous statements included elements of inner strength, love, and personal value. Several participants referenced their faith, and a belief that they were "chosen" to be the parents of a child with DS, " ... God chose us, because we are strong." (Brandon age 31, son age 2) Overall, there were elements of the benefits of the challenges that having a child with DS had brought to their life, which was anticipated from the SWLS scores for this cluster. They were connecting with their families and with others in the DS community.

“As a family we are very involved. (He then he goes on to describe the local and state wide organizations they are connected to.) So overall life is better than good.” (Bob age 46, son age 8)

Thriving cluster. The *Thriving* cluster (n=14) is characterized by scores on all three clustering measures that are higher than the other two clusters. The mean scores on the clustering measures for this cluster are: HHI (M=46.50, SD=1.87), CSI (M=21.60, SD 2.93) and SWLS (M=31.00, SD=3.49). The HHI score for this cluster is not only the highest of all the clusters; it is only a point and a half from the highest score on the scale. The range for scores on this scale is from 12 to 48. A score in this range would likely represent a persistent expectancy for a positive outcome and a strong sense of connection to others. The CSI mean score of 21.6 is also near the maximum possible score for the scale. The range of scores for this scale is 4 to 24. This was the highest CSI score of all the clusters and may reflect how the fathers in this cluster feel connected to their partners. Finally, the SWLS mean score for this cluster was 31.00; which again is quite high on a scale that ranges from 7 to 35. This score is considered a very high score and it reflects an attitude of enjoyment of life and deep satisfaction across various domains of work, family, and personal development (Diener, 2006).

It is important to note that there is a substantial amount of demographic information missing for this cluster. Three of the participants (21% of the cluster) did not give any demographic information beyond their gender. Yet, the demographics of this group are comparable to the demographics of the entire sample for this study. Demographics reported here and in Table 4.3 are

expressed as valid percentages of the available data. This cluster is comprised of 14 fathers ranging in age from 35 to 65, with a mean age of 43.6. All of the participants who responded were European-American White (100%) and all are married. The length of marriage for men in this cluster ranged from 7 to 27 years ($M=43.63$, $SD=8.54$), and was very evenly distributed across that range. Three of these fathers (27%) indicated that they are currently in a second marriage. All of these fathers had only one child with DS, and all of them had more than one child (2-5 children). The age of the child with DS ranged from ten months to 21 years old ($M=7.48$, $SD=5.36$), 80% of the children were between 3 and 9 years old, and two-thirds of them (63.6%) were girls.

The fathers in this cluster all had at least some college; 80% had completed an undergraduate degree, and 40% of the fathers had completed a Master's degree. Ninety percent of this group was employed full-time and one was retired. The income level for this cluster was diverse; 75% of respondents indicated an annual family income in excess of \$80,000, and the remaining 25% reported family income between \$40,000 and \$60,000. Again, most of these fathers (60.0%) learned of their child's diagnosis with DS after the child was born. Finally, in this sample, 90% identified as Christian, and one participant self identified as Jewish.

The high scores on all three clustering variables for the *Thriving* cluster were supported in the directed content analysis. As with the reports of fathers in other clusters, comments revealed a positive outlook in general. Most striking about the writing of fathers in this cluster was their mention of having

been “chosen” for their role as parents of a child with DS because of their personal strength, strength as a couple, and because of a strong faith.

“I was accepting of the diagnosis because it made sense to me that we would have a DS child because we are strong people and can handle this challenge.” (George no age or child information)

“From both of us, I think, we realized that ‘it was meant to be.’ And the ‘why us’ question, became, ‘if anyone, why not us.’” (Gil age 37, son age 10 months)

In terms of their marital relationship, these fathers indicated a high level of satisfaction in their marriages based on the CSI assessment. The analysis of the text data provided a more meaningful description of these marriages. When they talk about their marriage relationship the underlying tenor in this cluster is positive. Not unique to this cluster, these fathers told of differences between them and their wives in how they responded to their child’s diagnosis. Whereas the first cluster perceived differences with their spouse as negative, men in this cluster appear to find the differences with their wives to be a strength. Even though some of the stories revealed some level of friction, for fathers in this cluster the friction was balanced with an increase in information gathering and high commitment to the family. There was a distinctive positive element in their narratives about their wives’ and their own differential reaction. They said:

“She was much more cool about it all.” (Greg age 44, daughter 5 years)

“My wife took it much harder than I did and spent a good deal of time crying. ... it seems to me that she is more strict with [Jacob] than me. I can now see that it is very important to set boundaries for him but it was harder for me to understand that. This is what has introduced the most friction in our relationship.” (Garry no age or child information)

“...she was more apt to focus on local/directly applicable things (... the best therapists in the area, what school system ...). In contrast, I focused more on bigger issues such as how do individuals with DS integrate into the workforce, what are the true long term health issues, what can we expect a child with a disability to achieve.” (Gene age 41, daughter age 9)

The fathers in this cluster seem to be seeing a benefit to each partner’s response, whereas fathers in the *Hoping* cluster narrate differences between them and their partner as much more stress provoking.

When looking for themes of satisfaction with life in the text data, one point stood out distinctively for fathers in this cluster was a feeling that these fathers view having a child with DS as an experience that has made them better people with a better understanding of the meaning of life.

“She has made me look at life differently.” (Greg age 44, daughter age 5)

“He has helped me to understand what is important in life.” (Garrett age 43, son age 3)

“...this has made me a much more accepting individual.” (Gene age 41, daughter age 9)

“I am more aware...” (Gerard age 38, son age 8)

“I have a better understanding of I’ve also learned to be more understanding a lot more patient with everything that I do.” (Graham age 38, son age 7)

“Far more patient. ... More compassionate and more flexible” (Grant age 35, daughter age 6)

“Better understanding and insight.” (Gus age 52, daughter age 21)

“I think it has made me a better person with more empathy. It re-emphasized what elements in life are important. It helps me prioritize life.” (Gil age 37, son 10 months)

Perhaps their ability to frame the entire experience with DS as positive is a further reflection of the attitude of this group. Overall, the fathers in this cluster are thriving. They have high levels of hope, as expressed by their persistent positive attitudes, they are happily married, and they are more than satisfied, they express deep contentment and fulfillment with their life.

From the quantitative cluster analysis and the directive qualitative content analysis, a description of the clusters has unfolded which has provided a means for better understanding the fathers who make up these cluster groups. For a further level of understanding, the variable centered analysis was conducted to provide more specific information about how the clusters might be associated with fathers' coping strategies and behaviors.

Variable Centered Examination of Group Differences

An ANOVA was conducted next for the purpose of determining if there were cluster differences on coping behaviors as measured by the F-COPES scale which determines the use of a variety of coping behavior. The F-COPES composite score was used as the dependent variable and cluster membership was the independent variable. The ANOVA was significant, $F(2, 47) = 3.59, p < .05, \eta^2 = .133$. Hochberg's post hoc comparisons were used because the cluster sizes varied (Fields, 2005), and were examined to determine which groups were different from each other on the F-COPES composite score (see Figure 4.2). The post hoc comparisons revealed that the *Connecting* cluster was not significantly different from either the *Hoping* cluster or the *Thriving* cluster ($p < .05$) on the coping scale. However, the *Hoping* cluster ($M = 94.49, SD = 11.27$) was

significantly different from the *Thriving* cluster ($M = 109.07$, $SD = 17.94$), $p = .032$ (see Table 4.4). These results suggest that the coping behaviors, as measured by the F-COPES composite score, are not significantly different between the *Connecting* cluster and the *Hoping* cluster or between the *Connecting* cluster and the *Thriving* cluster. There was however a significant difference between the *Hoping* cluster and the *Thriving* cluster on the F-COPES composite score.

Figure 4.2: *F-COPES scores by cluster.*

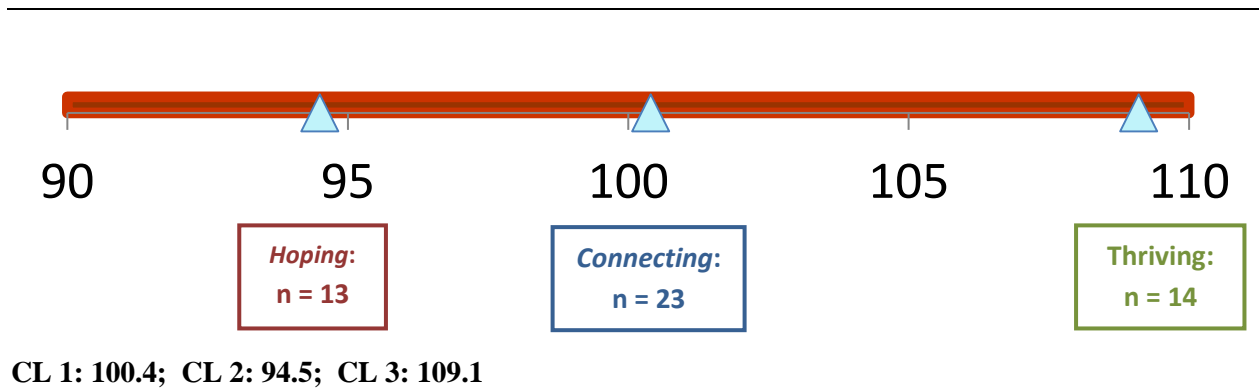


Table 4.4: *F-COPES for the clusters of fathers of children with DS*

	<i>n</i>	<i>M</i>	<i>SD</i>
<i>Hoping</i>	13	100.39	11.27
<i>Connecting</i>	23	94.48	17.94
<i>Thriving</i>	14	109.07	15.07

All three clusters had mean scores higher than the norm group mean of 93.12 for males (McCubbin et al., 1991). The results of the sampled population showed higher means than the outcomes of the sample population for the norming of the F-COPES measure. Despite the difficulties inherent in raising a child with a disability, the degree of overall coping for fathers in all three clusters exceeded that of the norm groups that have been studied.

Examination of the open ended questions as they related to coping behaviors revealed that each cluster demonstrated using somewhat different aspects of coping behaviors to address both the diagnosis of DS as well as their child's ongoing functioning.

Hoping cluster. The F-COPES composite score mean for the *Hoping* cluster was 95. This score is still almost 2 points above the normed mean of 93.12. Recall that the fathers in this cluster had the lowest mean scores on all measures of hope, satisfaction, and coping. Directed content analysis provides a better understanding of how these fathers meet the challenges of having a child with DS.

In the text data these fathers expressed an acceptance of life with DS, which sometimes sounded more like resignation. One father of a 7 year old boy explained that they have come to "...peace with his [son's] diagnosis." (Ross age 40) While another said, "...the diagnosis of Down syndrome is part of our world and our child's world." (Randolph age 61, son age 23). As noted in the cluster description, when these fathers discuss their current attitude about their child's diagnosis, the difficulty of daily life, and concerns about the future, "I

am always concerned about what would happen to her if we were gone,” (Rudy age 51, daughter age 25) are apparent. One father fluctuated between acceptance and frustration:

“Although I wouldn’t change any decision I’ve made, and I love him as much as a parent loves any child, there are days where I hate that he has Downs, that he has to struggle every day that he didn’t get the same chances that most kids get. That his future is extremely challenging, and I feel pretty helpless, because there’s little I can do to change it. I love how he’s 13 but still just a child, but I’m also saddened because he’ll never be a ‘normal’ teenager or adult. He’ll always be a little kid. ... Even though I feel we’ve been chosen, for whatever reason, to be parents of a special needs child, I wonder sometimes how different our lives would be if he was healthy. I had a much more positive attitude for years, but I’m feeling a lot older and tired. It wears on you, the daily struggle.” (Russ age 56, son age 13)

The scores on the HHI indicated that despite lower satisfaction scores, there was a strong element of hope felt by the fathers in this cluster. The text data told more about this aspect of the experiences of the fathers in this *Hoping* cluster. The coping strategies that one father describes includes both his direct action as well as his embracing strategies to achieve more favorable outcomes. This father’s coping behavior represents strong elements of hopefulness in the way he makes sense of his life with his daughter.

“I accept it [the diagnosis of DS], relish it, surrender to it, brag on it, am fulfilled by it, and what else can I say? She makes it easy, as she is such a fighter, just to survive. ... God put her in my life for a reason and at just the right time and I love the difficult path that I am now on. [Ally] has an IQ of 61, and at 9 is included in a general-ed first grade class with ESE pull-outs. I am extremely active in her education and development. We go to the Down Syndrome Center in [town name] twice a year for evaluations and support, we walk in the Buddy Walks, and I enjoy being a member of this special community. Ally also has severe ADHD, a visual impairment, and a clear diagnosis of terminal cuteness. She is full of energy and mischief and has taught me all about Dora the Explorer.” (Roy age 59, daughter age 9)

Connecting cluster. The *Connecting* cluster, the mid-performing group in the cluster diagram, had an F-COPES composite score mean of 100.39, which is 7.29 points above the norm for this scale. The directed content analysis unveiled elements of accepting the challenges of DS. It also provided understanding of the coping behaviors of reframing, a strategy used to put difficulties in a more positive perspective (McCubbin & Thompson, 1991).

“I wish she did not have Down syndrome (for her sake and mine), but I love her, accept her, and [would] not give her up for anything. She is an exceptional young woman that I am very proud of.” (Bryan age 56, daughter age 21)

“We will be stronger as a couple as we bind our hearts to cope with what’s been handed to us.” (Brock age 32, son age 2 months)

This is the cluster that had an SWLS score that indicated the possibility that challenges may be part of what brings them a sense of motivation. Indeed the conscious effort to look at the positive that comes through their comments gives credence to this as a possible conclusion. It is this effort to hold a positive attitude that seems to drive their involvement and advocacy for their children as well. Approximately half of the fathers described or alluded to involvement in DS community organizations that provide support for families.

“The biggest impact for me personally has been a ‘resetting’ of my life priorities. I was a career focused person prior to [Wes] being born, always looking at what job is next and in what location. Having [Wes] as part of my life shifted my focus and provided a greater balance between my home and work life. I no longer focus, as much, on what my title is at work or what job I am in next. I see my job as a means to an end. A necessity to support my family and their needs. This shift in focus has allowed me to get involved in the DS community in our area and see all of the opportunities that still need to be opened up to my son and others

with disabilities. It is these things where I want to spend my energy and time. All of this has given me a much different perspective on life, made me a happier person at work and at home, and provided a passion that I lacked prior to having [my son].” (Barney 33, son age 5)

Thriving cluster. The F-COPES composite score mean for CL3 was 109.07, which again is above the normed mean score of 93.12, this time by 16.88 points. This score is indicative of a cluster of fathers who are not just coping, but indeed, by every measure used in this study, appear to be thriving in the face of what many would describe as an extraordinary challenge.

The directed content analysis of the text data for CL3 provides many examples of coping behaviors. As illustrated in their responses to the open ended questions, the fathers in this cluster are activating all levels of coping behaviors, but most reflect what McCubbin (1991) termed internal coping behaviors. The fathers described efforts to seek information and advice from others in similar situations and a personal acceptance of their circumstances. Greg (41, daughter age 5) described his daughter as “... the light of our lives and we do all that we can to help her, ... with whatever resources exist.” Gus (52, daughter age 21) said, “We both were ... hungry to become educated,” and Grant (35, son age 6) described the personal impact of his son as being that he is “far more patient, able to receive gifts without feeling something must be given in return.” To further illustrate his level of personal acceptance, when responding to the query about his attitude toward his son’s diagnosis, Grant responded “What’s your attitude about your son having brown eyes?”

Many of the fathers' text responses indicated that they were using reframing, or meaning making, as a coping skill. As they described how they felt about their experience as fathers of children with DS. This cluster's responses centered on a perspective of "being chosen" to parent this very special child and they wrote about a belief that their experience had made them a "better person". These quotes are evidence of how they viewed fathering a special needs child as an opportunity for self-growth. The text data for this cluster are very positive and tell the story of fathers who are engaged with their children.

"The main impact of [my daughter]'s diagnosis on me has been to heighten my awareness of those with disabilities and in turn, this has made me a much more accepting individual. I was always aware of those with intellectual disabilities (and physical disabilities as well) but I was not as accepting or sympathetic to these individuals as I am now. The other major impact has been the opportunity to meet many wonderful people in the DS and disabled community that I would have never been introduced or become friends with if it was not for [my daughter]. We have been fortunate to broaden not only our group of friends but truly enhanced our lives because of these friendships and connections. ... As with any child, there are always apprehensions about the future but I believe these are increased when you have a child with a disability. My 'current' attitude is a 10 as we are very fortunate to have a well adjusted, fun, inquisitive stubborn 4th grader who happens to have Downs syndrome. Can she be difficult, yes, can she be obnoxious, yes, can she be disruptive, yes, but so can our other two children. I would say that [my daughter] more often displays these negative behaviors but she is also much more caring, sympathetic and responsive to the needs of others. You have to take the good with the bad and in our case, [my daughter] has much more good than bad." (Gene 41, daughter age 9)

Results Through a Theoretical Lens

The final consideration in the directed content analysis of the text data was to be aware of themes of ambiguous loss. None of the open-ended

questions referred openly to the concepts of ambiguous loss. The fathers in this sample did however reference their experience, especially when they learned of their child's diagnosis, with a sense of loss. The fact that the fathers discussed their experiences with the ambiguity of their child's diagnosis and life adds considerable validity to the use of this theory for studying this population and deepens an understanding of all three clusters of fathers.

Hoping cluster. As Americans it is easy to slip into an individualistic or mastery mindset that presumes good outcomes are the reward of hard work. The sense of mastery can help one to feel that they have the agency to manage stressful situations yet, Boss (1999, 2006) cautions against the mastery mindset, as it can obstruct a healthy grieving process of an ambiguous loss and weaken resiliency. It can block the flow of care and support that provides sustenance through the ebb and flow of hope and hopelessness that comes with the chronic dissatisfaction that appears to be persistent in the *Hoping* cluster. When the source of the ambiguity will not go away, Boss (1999) posits that people become increasingly creative in their ways to manage. This cluster appears to embrace the "nose to the grindstone" individualistic approach as they push themselves, and their children with DS, to their greatest potential. This expression of acceptance, with resignation, may help them make meaning of the stressors which embrace them daily.

"I was totally disappointed. I called everyone...family friends, coworkers, etc. to let them know that he was healthy. Then I had to call everyone back to let them know that he had Down syndrome. It was like the child that I had always wanted was not going to happen. I first wanted to deny the diagnosis." (Ralph age 46, son age 16)

This strategy of mastery continues to appear as the fathers in this cluster discuss their current attitudes toward the child as well as when they talked about the time of diagnosis. As these dads attempt to persevere in the face of ambiguity, the lack of certainty allows them to hope for a more positive outcome. Ultimately it is the significant presence of hope for a better outcome that permeates both the statistical and the text data for the *Hoping* cluster.

“We both expect him to behave and contribute to our family. We want him to achieve as much academic success as possible. We want him to communicate better, so we can truly understand his cognitive level.”
(Ross age 40, son age 7)

Connecting cluster. While examining the *Connecting* cluster fathers’ stories of learning about their child’s diagnosis, it is easy to begin to get a sense of the fear, and the uncertainty that frequently characterized the participant’s sense of loss. There was evidence of an ambiguous mourning process for the child and the life that, though perhaps still undefined, was already in some sense lost. This sense of ambiguity was spread among family and friends as well when they too attempted to determine how to cope with this new, perhaps unexpected life experience. That path often appeared to begin with a stumble.

“My wife was in shock and then in depression for some time. (upon learning their child’s diagnosis) I, on the other hand, went into anger and denial for a short period of time. When we were first married, we were having trouble getting pregnant and carrying the baby to full term. So, we began to think about adoption.... However, once we had our first child, I had pushed that to the back of my head. So, when we had the second child, your hopes and dreams take a beating at first, until you realize all will be ok. For my wife, people were sending condolence cards

instead of congratulations and that paired with post partum depression really took its toll.” (Bruce age 41, son age 5)

There were other fathers who told similar stories of the reactions of family and friends, leaving no doubt that the birth of a child with a developmental disability can be an ambiguous experience. Still the fathers’ narratives in this cluster continue to focus on the ways that they are satisfied with their life and the engagement strategies they choose to use to cope over time. For the members of this *Connecting* cluster the news of the diagnosis frequently progressed to a commitment to action.

“Had [my son] not been born with Down syndrome I would not have met a fraction of the people I have met, gone to a fraction of the places I’ve gone, or done a fraction of the things I’ve done. His birth changed my career, my world view, my involvement in public policy, our choice of where we live, and my education level.” (Blane age 43, son age 10)

The theory of ambiguous loss provides a framework for making sense of the experiences of the fathers in this cluster. This *Connecting* cluster illustrates Boss’s contention that “ambiguity does not have to devastate” (Boss, 1999, p. 133). The fathers in this cluster highlight a positive attitude in their text data. Their positive attitudes are illustrated in their sense of direction which permeates their responses. These fathers talk about the ways they and their spouse/partner share their responses to their child. They identify both short and long range goals for their child and they discuss their involvement with various groups that serve others who live with similar concerns regarding the ambiguity of their child’s development. Boss (1999) described this sense of focus as the ability to take risks because of having determined how to live with

the unknown. She quoted Gilda Radner who described this as “delicious ambiguity” – an inability to control the fearful response, but a willingness to take responsibility for daily life (Boss, 1999, p. 135).

Thriving cluster. The *Thriving* cluster appears to personify what Boss (1999) calls ‘making sense out of ambiguity.’ The unifying theme for this cluster is their rather persistent ability to attach substantial meaning to their experience. This is the cluster which not only frequently referenced the concept of a “higher good” or deeper meaning, they related that sense of “being chosen” to their personal development at a moral level. There were elements of this process in all three clusters, but for this cluster this theme represents the focus. For the large cluster, the *Connecting* cluster, the idea of being chosen because they were capable translated to commitments to action – serious involvement in proactive ways to turn their circumstance into a benefit for others. For the *Hoping* cluster, the concept of being chosen and the subsequent personal growth was expressed more in a manner of determination and an almost stubborn defiance to survive in spite of it all. However, for the *Thriving* cluster the understanding of being chosen seemed to be the goal, in and of itself. Their sense of being chosen led to personal development and being a “better” person, with that perspective, came peace and a sense of personal value.

The *Thriving* cluster provides an opportunity to observe a group of fathers who have described a worldview that embraces the ambiguity of a reason for life’s events and allows these fathers to find meaning not in the ‘tragedy’ of

having a child with DS, but simply in the experience of fathering. The fathers' stories in this group are ones of finding their way to a peaceful acceptance of what is. By choosing to attribute positive meaning to their life as fathers of a child with DS, they express positive coping strategies and behaviors. The *Thriving* cluster appears to have an attitude of acceptance and a goal of harmony with the ambiguous circumstances in their life. Boss (1999, 2007) describes this type of behavior as meaning making. For some it comes from a foundation of faith, for others from a more existential worldview. The search for meaning guides how stress, hope, coping, and grieving interact in a person's life. These fathers experience the ambiguity of their situation, and they make it a meaningful part of their life. They are thriving where they are.

A father summed up the feeling in that group when he told the story, well known in DS circles, of a trip to Holland.

“You make all these plans and dreams for a lifetime trip to Italy. On the way, your plane is rerouted to Holland. Now you can spend a lifetime complaining about how you were rerouted and didn't get to see Italy...or you can make the effort to open your eyes and see the wonderful things about Holland.” (Gage unknown age, unknown child data)

Chapter 5

Discussion

There is evidence that families and fathers of children with disabilities are much like families of typically developing children, they have both stressors and joys (Brotherson & Dollahite, 2007). Research on fathering has often been through a deficit lens that focused on weaknesses and shortcomings (Hodapp, 2007). Furthermore, research on families of children with developmental disabilities historically focused on the stressors and obstacles they faced (Hornby, 1995). More recently scholars have called for non-deficit paradigms for family studies (Antonovsky, 1990; Brotherson & Dollahite, 1997; Grant et al., 2007).

The current study was designed to explore the roles that hope and satisfaction play in the experiences of fathers of children with DS. Using a person oriented, non-deficit model, both quantitative and qualitative techniques were employed to explore a secondary data set within the theoretical framework of ambiguous loss. This unique perspective showed that indeed there was heterogeneity within the sample, as identified with a cluster analysis, and attitudes of hope and satisfaction played a role in describing different coping responses fathers had to their experiences. The qualitative directed content analysis provided a more comprehensive understanding of the fathers in each cluster. A discussion of the study will be organized into three parts beginning with a discussion of the main conclusions for the three research questions. Then an overview of the strengths and contributions of the

study; plus the limitations of the study will be critiqued. Finally, implications for future research as well as considerations regarding applications of the study for professionals will be presented.

Main Conclusions of the Study

The results of this study provided a way to examine the hope and satisfaction attitudes of fathers of children with DS, as well as the various coping strategies and behaviors they employ in their lives as fathers of children with DS in a non-deficit model. In response to the first research question, which sought to examine if there were patterns of hope and satisfaction within the sample, a cluster analysis found that there were three groups of fathers who differed in their hope and satisfaction attitudes. The three groups that were found differed on their hope and satisfaction scores. An ANOVA which examined the three clusters on their F-COPES scores, found differences in coping strategies and behaviors, in response to the second research question. The first cluster had the lowest scores for hope, satisfaction, and coping. The second cluster's scores were between the other two clusters and it had the largest number of members. The third cluster had the highest scores on hope, satisfaction, and coping. Finally, guided by the third research question, a directed content analysis of the text data provided further support for a richer understanding of the differences in each cluster.

The *Hoping* Cluster. This cluster had the lowest scores of the three clusters on all three of the hope and satisfaction measures. The hope score was the highest of these three. The text data related to hope and satisfaction

themes provided further insight as to what those scores might mean for these fathers. Their narratives revealed an attitude of resignation in their acceptance of the DS diagnosis and examples of the dimension of hope that Herth (1992) described as a sense of hope for a better outcome.

The coping scores for this cluster were above the normed mean for the scale. Insight as to how these fathers were utilizing coping strategies and behaviors was revealed in the text data. Evidence emerged of the types of coping behaviors that Boss (1999) identified as individualistic, in response to ambiguous losses. Perhaps their hope for a better outcome may have led to the individualistic behaviors that guided their 'determined to succeed' approach to their relationship with their child and their adjustment to living with DS. This behavior is seen in their narratives as they told about pushing their children to participate, achieve, and try harder at all they do.

The fathers in this cluster told of differences from their partners in their responses to their child's diagnosis as well as their current situations. These fathers face the ambiguity and their loss daily and do not minimize it; their way of overcoming it and maintaining hope is by taking action with their child - pushing. Both the satisfaction with life scores and text data revealed concerns for the negative potential of chronic stress within this cluster of fathers. For this cluster their coping strategies that focus on individualistic and mastery oriented behaviors may prove costly in the long run.

The Connecting Cluster. The largest group of fathers was found in the *Connecting* cluster 2. This group had high scores, which fell between the other

two clusters, on all three clustering variables of hope and satisfaction. Three things related to hope and satisfaction were prominent in the text data from this cluster. One was references to the similar response they had with their spouse to both the diagnosis of DS and their approach to parenting. Another was the comments about their faith, and third was frequent comments about their connection to the DS community. These responses to the open ended questions are illustrations of connectedness with others in life and spirit, which Herth (1999) identifies as a dimension of hope. These comments also demonstrate the sense of satisfaction these fathers have in their relationships and with their life. Diener (2006) indicated that satisfaction with life scores, like those found in this cluster; indicate that challenges may provide these fathers a sense of motivation. For this cluster, that motivation appears to manifest in the positive coping strategies they exhibited.

The mean F-COPES score for this cluster was high. Their participation in the DS community is an example of the activation of social support networks described by McCubbin & Thompson (1991) as a coping behavior. The directed content analysis revealed that these fathers wrote about significant involvement in social support groups and DS organizations. A high level of involvement in the DS community as a commitment to action provides an example of positive coping in the face of ambiguous loss. While unable to control the fearful feelings that arise when faced with ambiguity, the fathers in this *Connecting* cluster choose to take action in the face of the uncertainty.

The *Thriving* cluster. Finally, the *Thriving* cluster was the highest performing cluster on the three clustering variables. The text data again provided a further description of the hope and satisfaction of these fathers. This group of fathers discussed their sense of strength. This was made explicit in their comments when they stated that having a child with DS made them even stronger. They discussed a sense of being chosen for their role as a father of a child with DS. Overall, the fathers in this cluster expressed an attitude of deep satisfaction with various aspects of their life related to work, family, and personal growth. Their text data related to coping was similar as they referred to the kinds of behaviors McCubbin & Thompson (1991) called reframing coping behaviors. Their reframing behaviors appeared to provide them a way to give meaning and purpose to their life and the life of their child.

While it may be tempting to say that this cluster did not experience a sense of ambiguous loss, Boss (1999) describes the behaviors, like those in the text of this cluster, as the ability to ‘make sense’ of the ambiguity of their circumstances. The text data provides evidence of their sense of ambiguity and loss, but it also provides evidence of how they make their experience meaningful on a very personal level.

The findings of this study confirmed that indeed there were differences within the sample population on measures of hope and satisfaction and that those differences translated to differences in coping behaviors. As anticipated, the directed content analysis provided richness to the understanding of the clusters and a fuller picture of the lived experiences of this particular sample.

This study contributes to our understanding of hope and satisfaction in families with a child with DS by altering the deficit-based lens of viewing a child with DS as an adversity.

Critique of the Study

Strengths and Contributions. This study contributes to the current body of knowledge in several ways. Hawkins and Dollahite (1997) expressed concern that deficit models of research on fathering over emphasize inadequacies, and Hawkins and Palkovitz (1999) advocate for research to examine varied aspects of fathering, including internal (i.e. cognitive, affective) aspects of interaction with children. This study makes a contribution to the knowledge about generative fathering because it looks at the personal attitudes and behaviors that these fathers have toward caring for their children. Methodologically, the person-oriented mixed method of the study was both unique and informative, and responds to the call for a non-deficit framework when researching fathers of children with disabilities. Furthermore, it makes a contribution to the literature using the theory of ambiguous loss.

Methodology. The current study was designed to explore the roles that hope, satisfaction and coping might play in the experiences of fathers of children with DS. Individuals are unique, but the patterns of their behaviors tend to be limited. The purpose of person oriented research methods is to capture those patterns that provide a clearer understanding of the development of individuals. To achieve a person oriented perspective for this study as proposed by von Eye and Bogat (2006), a cluster analysis was used to explore

the sample of fathers on their attitudes of hope and satisfaction. The groups were further validated by determining if the group differences held up when they were examined on their coping behaviors – a variable that was not used in the clustering techniques. The follow up variable centered analysis provided further evidence of the between cluster differences. Finally, as recommended by scholars who advocate person oriented techniques (Bergman & Trost, 2006; von Eye and Bogat, 2006), the clusters were interpreted in the context of theory.

A person oriented perspective was pursued because it allowed a more focused understanding of the participants in the study. When data is aggregated researchers can easily fall into interpretations based on mean scores. In this study it would have been easy to describe the sample of fathers as high functioning on all measures of hope, satisfaction, and coping. The loss in so doing would have been not finding the nuances that described their differences. For example, the differences between clusters on their level of satisfaction with life would have been missed. The mean score for the entire sample indicates a group of fathers who are high functioning. However, that aggregate measure overlooks the concern regarding the element of chronic stress for the *Hoping* cluster. Understanding this difference in functioning and development for that group of fathers provides a better understanding of their experiences.

The person oriented perspective of this study was further expanded by the use of the qualitative directed content analysis. A better understanding of

the father's perspective through qualitative methodologies has been advocated by Hornby (1995). A weakness of self report measures is that they preclude a deeper understanding of what drives a group to tell their story, and they lack specific information to understand the personal meaning involved in a participant's experiences. This concern was addressed in this study through the use of the qualitative directed content analysis of the available text data.

By including this further level of analysis, a much richer understanding of the experiences of these fathers of children with DS emerged. Through use of the directed content analysis, a better understanding of the marriage relationship was also discovered. The text data revealed that different outcomes for couples who responded differently when they learned of their child's diagnosis and in their parenting style meant different things – those differences were a point of contention for the *Hoping* cluster, but a point of strength for the *Thriving* cluster. It was the directed cluster analysis that provided rich descriptions of participant's hope and satisfaction attitudes, as well as more specific evidence of their coping behaviors.

Non-deficit model. This study confirms speculation that the non-deficit model for research on this population is both appropriate and informative. It provides more understanding about the experience of parenting a child with DS, especially from the father's perspective and it is a starting point for further research. Very few studies examine the experiences of fathers. Hence, taking an in depth look at the fathers in this study helps to identify the needs and challenges specifically for fathers. The choice of measures, as guided by the

research questions, specifically investigated what was working in these fathers' lives. Furthermore, this study focused on transition points in these fathers' development – both when they learned of their child's diagnosis and as they were interacting with them at the time of the study. By intensively studying this small sample of fathers with a mixed methods design, it was possible to derive a better understanding of the patterns of development in their lived experience.

One of the goals of person oriented research (Bergman & Trost, 2006) is to better understand the processes of development. The mixed methods of a quantitative cluster analysis, validated with a variable centered analysis, and followed by a qualitative directed content analysis provided an opportunity to explore the dynamic developmental processes of a group of high functioning fathers of children with DS with relative simplicity. Interpreting those finding in the framework of the theory of ambiguous loss provides further clarity in understanding the different trajectories that these fathers experienced. The application of theory further provided a meaningful interpretation of the data.

Use of theory. This study has expanded the application of the theory of ambiguous loss. In 2007, Boss reviewed the progress of research conducted using the theory of ambiguous loss and called for further research to better understand the nuances of the effect of ambiguous loss on development. This theoretical model is well suited to the non-deficit salutogenic perspective of this study because, by using ambiguous loss as the theoretical framework, the

focus is on the ambiguity of the circumstances of having a child with Down syndrome as opposed to focusing on short comings of the fathers.

Most of the time when a child is born with DS the parents do not know until the birth, and thus have not had the time or opportunity to prepare for their new life circumstance. If parents know their child will have DS before he or she is born, they have the opportunity to make some preparations for what lies ahead. More often, however, the DS diagnosis does not come until after birth. Whether parents learn the diagnosis of DS before or after the birth of their baby, ambiguity remains as to the long term functioning of their child. DS is a permanent, pervasive condition that can express with mild, moderate, or severe symptomology. Whatever that turns out to be, parents must adapt to those needs every day. For some, the element of loss seemed less significant, for others the ambiguous loss framework may provide them a crucial pathway for their coping process to progress.

Life is filled with ambiguity. It is not just the experience of having a child with a disability – it is the experience of living. The sense of control many people have is actually an illusion. There is never a day we truly know what will happen, only parameters in which we have become comfortable responding to experiences. The use of the theory of ambiguous loss in this study provided the opportunity to explore the responses of this group of fathers to a life experience outside typical parameters.

Limitations. As with all studies, there are limitations that should be considered when determining how to interpret and generalize results. This

study was specifically focused on fathers of children with DS; therefore it is important that the findings not be generalized to all fathers or to fathers of children with other developmental disabilities. Another limitation was the sample selection process. Since the call for participants went out through DS organizations, the sample was limited to people who chose to visit the web-sites of DS support organizations nationwide, and then self selected to participate. Thus, the sample was limited on socio-economic and ethnic factors to those who use internet sites for connection with others and to find information. This limitation is seen in the lack of demographic diversity of the sample. The sample for this study was primarily comprised of well educated, higher income, Christian, white males. As a result, it is unreasonable to assume these same cluster findings would exist in a sample of fathers of lower socio-economic and/or education status. Also, this study relied solely on self-report measures. The absence of other methods of assessment (e.g. behavioral observations) prevents verification of fathers' reports.

A further limitation is the lack of information regarding the level of functioning of the child with DS, and/or the presence of any co-morbid conditions. A few fathers discussed their child's level of impairment. Several in CL1 specifically referenced lower levels of functioning. This brings up the question of child functioning by cluster, is there a difference? The answer to that query is not available for this sample. The findings of this study indicate that this would be valuable information in future studies, but difficult to define or operationalize.

Information regarding family structure issues was also limited. This study was restricted to fathers who were married; which limits the generalizability of the findings of the study. There are still unknowns as to the attitudes and coping responses of single fathers. Furthermore, there was no data regarding siblings and their contributions to the family system.

Some of the questions in this study focused on the time of diagnosis and some on the attitudes and behaviors at the time of data collection. This made the findings challenging to interpret. An ideal design would be longitudinal. It would be useful to follow a group of fathers of children with DS over time. This would also address the confounding effect of the variation in services available at different points in time and in different locations.

A final consideration relates to interpreting the coping data; which could have been addressed more thoroughly with a larger sample size. One tangle to this issue is that the participants may be reporting more coping behaviors because they may have more problems. Furthermore, this was one of the measures that asked about the time frame when the child was first diagnosed; however, it appears that utilizing more behaviors at that time may be associated with being in the cluster of fathers with higher hope & satisfaction, but there could be many other factors (including degree of disability) that would help to explain this apparent finding.

Directions for Future Study and Applications for Practice

One goal of research is to discover ways that the findings can be useful and transferable (Richards & Morse, 2007). The directed content analysis used

in this study provided an especially in depth dimension to the person-oriented methodology. From the text data a richer, fuller description of the clusters provided insight for understanding the lower CSI scores found in CL1. From the participants' responses, descriptions emerged of conflict with spouses (both to their child's diagnosis and in their current acts of parenting). This conflict can impact the foundations of intimacy for fathers and consequently have an influence on outcomes for the father-child relationship (Doherty, 1997; Brotherson & Dollahite, 1997). The work of Stanley, Allen, Markman, Sai, Blonstrom, Thomas, Schumm, and Bailey (2005) addresses the efficacy of marriage education in various populations, including classes with couples in high stress circumstances.

Marriage education classes could be developed and presented to this population that addresses some of the specific concerns that were presented by participants in this study (e.g., conflict resolution skills). Confidence in a skill set for addressing difficult issues within the couple relationship could support the couple in finding mutually satisfactory solutions to various issues they may face (Markman, Renick, Floyd, Stanley, & Clements, 1993). It is possible that, with new relationship skills, improvement in couple functioning could ameliorate some of the risk associated with raising a special needs child.

By exploring hope and satisfaction, as well as coping, among fathers in families with a child who has DS, the opportunity of other families in similar circumstances to overcome some of their challenges may be increased. The attitudes and skills identified in this study can be used to develop

psychoeducational workshops and enrichment programs. In addition, one or more of these skills could be addressed in individual or family interventions. Such interventions create the possibility of strengthening a family before the demands of a special needs member become overwhelming. Workshops based on these ideas could be created for couples to attend after they receive a pre-natal diagnosis. For couples seeking guidance in how to prepare for their unborn child with DS, workshops such as these could be very helpful. Likewise, such workshops could provide valuable support for parents of newborn babies who are diagnosed with DS.

There will always be value in studies that provide information about the effectiveness of services and interventions for those persons who have DS and various members of their family. Although this study looked at coping strategies and behaviors of this sample of fathers as an aggregate score, a study examining the subscale scores of the F-COPES may prove to be more informative. A longitudinal study of fathers' coping strategies and behaviors from birth to adolescence may uncover possible shifts over time. Such a study that also included information regarding the involvement with various available services and the extent of the child's disability could provide further understanding of the coping mechanisms for fathers. An examination of the F-COPES subscale scores may provide a way to more explicitly understand coping factors for these fathers. The various subscales of coping could be used to further evaluate ways to provide support for the various coping techniques

and how they could be enhanced. Specifically, more attention could be given to fathers' needs and their access to social support.

The experiences of other family members also warrant attention. Very few dyadic studies have been conducted that examine the interaction of partners' attitudes and behaviors. Siblings, grandparents, and other extended family members may also play a significant role in the care and support structure around a child with DS. Some of the fathers in this study mentioned concerns about their other children and the influence, both positive and negative, of having a sibling with DS. An examination of family coping behaviors could influence the availability of services for all members of the family.

It is important to remember that effective and sustainable programs and services are needed to provide support for families, as well as children, with DS. The results of this study highlight two important areas that could be addressed with training workshops and in marital and family therapy; coping behaviors and couples satisfaction. Services, which address and work to develop client skill deficits may contribute to increased self-esteem and help establish a sense of control. Coping behaviors are an expression of a skill set and effective coping skills can be learned (Edgar, Rosberger, & Collet, 2001; Park, Leidy, Schodield, Miller, & Morris, 2008). Programs designed to teach coping skills could be geared toward the specific needs of the DS population and have the potential of supporting all family members with more effective coping behaviors. Furthermore, the possibilities for use of the theory in the development of these intervention and program pieces are vast.

The value of this study for practitioners is, in part, the identification of the father's experience within the framework of understanding that emerges from the lens of ambiguous loss. By identifying the circumstances of their life with DS as a type of ambiguous loss, it provides practitioners a path for supporting fathers in growth and personal development with the understanding that at least some of their concerns are related to their ambiguous circumstances and not due to some personal flaw. This can provide an opportunity for reorganization of one's thinking and thus effect the types of solutions they will seek.

Essence of the Study

When considering each of the clusters, the *Hoping* cluster members appeared to deal with the ambiguity of their situation by infusing their life with an attitude of hope. Although it appears they have struggles in their marital relationship, their text responses still resonated with elements of hope for the future and a push for greater achievement. It appears the *Connecting* cluster experienced ambiguity and loss of the child they expected to have, yet, they charged ahead with an action oriented approach towards acceptance and greater social change. Finally, the *Thriving* cluster was the most successful at creating positive meaning in the midst of the ambiguity of their child's diagnosis and what the future would hold.

This study will help direct future research in determining key qualities that are present in resilient fathers; which can guide both researchers and

practitioners toward establishing supports for fathers who are coping less successfully.

Fathers of children with DS have been an understudied population. This study has done much to expand the use of ambiguous loss as a theoretical framework and has illustrated that a non-deficit model is an appropriate framework for research dealing with fathers of children with DS. The role of hope, satisfaction, and coping combined has helped provide a clearer understanding of the lived experiences of these fathers.

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Appendix

PDF of online survey – separate attachment