CAREGIVERS OF INDIVIDUALS WITH INTELLECTUAL DISABILITY: AN EXAMINATION OF THE DYNAMIC PROCESS MODEL OF CAREGIVER WELL-BEING

A Dissertation

by

TANIA RENDÓN SANTIAGO

Submitted to the Office of Graduate and Professional Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

Chair of Committee,	Timothy R. Elliott
Committee Members,	Daniel Brossart
	Oi-Man Kwok
	Rebecca Schlegel
Head of Department,	Shanna Hagan-Burke

August 2017

Major Subject: Counseling Psychology

ABSTRACT

Through the years, scholars have made various developments in the area of caregiver research. As a result, policy makers and program developers have been able to better assist individuals with Intellectual Disabilities (ID) and their families. Additionally, convoluted caregiving concepts have been examined in an array of contexts and populations. Contextual models are vital in understanding the complex and dynamic experiences of caregivers. Although research has shown that some caretakers experience caregiver burden, other findings indicate that caregivers adapt well to their caregiving role.

The purpose of the current study was to examine caregiver well-being through the dynamic process model of well-being. In contrast with previous work, this study examined constructs that have not yet been studied within caregiving models. More explicitly, the elements of our model consisted of caregiver positive supports, presence of meaning in life, search for meaning in life, meaning in caregiving, and aggression exhibited towards caregivers. Outcome variables included physical and mental health composite scores that were used to measure well-being. Furthermore, our model was tested with a sample predominately consisting of Latino caregivers, which is a population that has received little attention in this line of research. It was hypothesized that presence of meaning, search for meaning and meaning in caregiving would serve as mediating factors to caregiver well-being. Results showed that our meaning variables did not function as mediating factors for caregiver well-being. Although our data did not

support our hypotheses, it was found that search for meaning contributed negatively to caregiver mental health scores, and that caregivers who experienced aggression from care recipients reported lower levels of meaning in caregiving. Lastly, our findings echoed previous findings indicating that positive support systems had a positive impact on caregiver well-being. The majority of our participants were Latinos; therefore, ethno-multicultural implications, such as marianismo, familism, and caregiving barriers related to immigration are discussed.

DEDICATION

       This dissertation is dedicated to my family. To my mother and father who have taught me the ethic of hard work and perseverance. To my brothers, niece Victoria and nephew Nathaniel who have inspired me to continue with this project even during challenging times. To my dog Bailey, my beloved companion and best friend who gave me strength through her unconditional love (Until I see you again under the Rainbow Bridge, 2009-2015). Finally, to my partner who provided me with continuous support throughout this entire journey.

ACKNOWLEDGEMENTS

CONTRIBUTORS AND FUNDING SOURCES

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

CHAPTER I

INTRODUCTION

Everything can be taken from a caregiver but the human freedom to choose his or her attitude in any given set of circumstances. This inner freedom determines whether a caregiver becomes a plaything of circumstance or an active participant in the caregiving situation (Frankl, 1963 as cited in Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991).

Historically, individuals with a severe intellectual disability (ID) have required some degree of assistance from others including neighbors, friends, and family members (Cummins, 2001; Reinhard, Given, Petlick, & Bemis, 2008). Due to the demands of caregiving tasks, caregivers typically face an array of difficulties related to stigma, social inclusion, lack of social support systems, and financial resources (Resch, Benz, & Elliott, 2012). Scholars have made various advancements at a policy, societal, and scientific level to facilitate better living conditions for individuals with disabilities and quality of life of caregivers through assessment tools and program initiatives (e.g., Elliott et al., 2014). In addition, elaborated theoretical models have served as a way to mutually examine various contextual factors associated with caregiver well-being (e.g., Resch et al., 2012). Nevertheless, more scientific inquiry is required in order to aid scholars and professionals in the development of new theory and application.

Scheerenberger (1983) explains that in the 19th century the majority of parents who had children with ID were required to provide care in their own residence due to

lack of resources and community services. As a result, many economically disadvantaged families were not able to provide alternative residential settings for their children and relatives. During this time individuals with ID were perceived in society as "unfortunates" or "innocents" (Scheerenberger, 1983). Cummins (2001) suggests that these views changed with Darwin's philosophy of "natural selection" and "survival of the fittest," and individuals with ID were later seen as "undesirable." In addition, society isolated them and sterilization practices were used to prevent them from reproducing. Consequently, many individuals with ID were institutionalized and marginalized, which prompted professionals and advocates to question if this environment was the best option of residential care (Cummins, 2001). During the 1970s residential changes began to occur at a societal and policy level (Cummins, 2001). Nirje and Wolfensberg were prominent advocacy figures, and their efforts contributed to policies that encouraged living conditions that conformed to the general population standards (Scheerenberger, 1983). In their arguments, they included terms such as "normalization" and "least restrictive environment" (Scheerenberger, 1983), terminology that is still used today by government agencies that offer community-based programs to individuals with ID and their caregivers (e.g., Texas Department of Aging and Disability Services, 2015).

Deinstitutionalization helped to improve care for individuals with disabilities, and in more recent years it has also contributed to savings in government funds (Arno, Levine, & Memmott, 1999; Cummins, 2001). The National Alliance for Caregiving and AARP (2015) reported that 43.5 million adults have provided unpaid care for another individual within the past year. It was also found that the majority of caregivers were

females (60%) and relatives (85%) who provide care to individuals who suffer from long-term physical conditions, cognitive deficiencies, and chronic illnesses. Caretakers are typically responsible for providing assistance with an array of personal tasks referred to as activities of daily living (ADL; e.g., bathing, dressing, taking medications) and instrumental activities of daily living (IADL; e.g., transportation, shopping, and housework; National Alliance for Caregiving and AARP, 2015; Reinhard et al., 2008). Additionally, caregivers are required to interact and collaborate with service providers to ensure care recipients receive adequate services. Currently, it is estimated that approximately 63% of caregivers are forced to engage in advocacy roles in order to have their needs met (National Alliance for Caregiving and AARP, 2015).

During the past few decades drastic changes have occurred in residential services for individuals with disabilities due to Medicaid home and community-based service (HCBS) waivers (Vladeck, 2003). Reports showed that residential services in state-operated institutions declined in the United States from 1967 (195, 000) through 1998 (52, 800; Braddock, Emerson, Felce, & Stancliffe, 2001). However, it was in 1999 when the Olmstead court decision established that the Americans with Disabilities Act was required to provide services to Medicaid recipients who had a disability in the "least restrictive environment that is practicable" (Khran & Drum, 2007). As a result Medicaid waiver services presently offer residential services such as foster care companion/host companion care and supported home living services in family homes to relatives and non-relatives of individuals with an ID (e.g., Texas Department of Aging and Disability Services, 2015). Today, program developers promote caregiving practices that involve

an environment that fosters development, community inclusion, and psychological well-being (Cummins, 2001). Scholars are also making efforts to examine factors associated with community-based programming to advance delivery of services (e.g., Elliott & Parker, 2012; Elliott et al., 2014; Patnaik et al., 2011).

Researchers have developed rigorous methodologies to investigate a plethora of topics with the purpose to identify risk factors to caregiver burden (e.g., Magana, 1999; Wikler, Wasow, & Hatfield, 1981), such as care-recipient characteristics, maladaptive behaviors and severity of diagnosis (Erosa, Elliott, Berry, & Grant, 2010; McClintock, Hall, & Oliver, 2003). Additionally, studies have focused on deciphering the enigma of protective factors among caregivers such as appraisals towards caregiving including meaning in caregiving, and threat and growth (Farran et al., 1991; Resch et al., 2012). Despite past and current advances in this line of research, shortcomings in the literature continue to exist. Caregiver burden, well-being, and coping are convoluted concepts that require extensive methodological and contextual considerations. For that reason, more contextual models examining multiple factors simultaneously are necessary to shed light to the existing findings (e.g., Resch et al., 2012; Wallander & Varni, 1998).

Research has consistently revealed that the quality of life of caregivers on average is lower than individuals who do not have a child or relative with a disability (e.g., Green, 2007; Irazabal et al., 2012). This is particularly true when the care-recipient has high dependent needs, is aggressive, non-verbal, and has comorbidities with other diagnoses (such as autism; Wade, Taylor, Droter, Stanein, & Yeates, 1996). Moreover, family caregivers of individuals with intellectual disability tend to have higher rates of

depression, stress, anxiety, greater disruption of family plans, financial difficulties, restrictions in social activities, and more medical problems than non-caregivers (Bouma & Schmeitzer, 1990; Winefield & Harvey, 1994). Despite these findings, inconsistencies on how much of this burden contributes to psychopathology persist (Baker, Blacher, Kopp, & Kraemer, 1997). Subsequently, researchers have begun to shift their focus at identifying factors that may alleviate caregiving burden (Baker et al., 1997). Scholars now examine both positive and negative aspects of caregiving to better understand what factors contribute to caregiver well-being (Resch et al., 2012). Resch and colleagues (2012) explored caregiver well-being through the dynamic process of well-being model. Their findings suggest that positive aspects are of major importance in respect to caregiver well-being.

Purpose

The purpose of this study was to extend the findings of Resch and colleagues (2012), which examined the dynamic process model of well-being among parents of children with an ID. In contrast with this study we utilized different constructs such as aggression toward caregiver, presence of meaning and meaning in caregiving within this model. Mental health and physical health were used as indicators of quality of life; therefore, for the purpose of this study higher composite scores on these two measures were considered higher levels of well-being. In addition, our sample was more inclusive, and an array of formal and informal caregivers (e.g., host companion caregivers/parents/relatives, day habilitation staff, and supportive home living staff) of both children and adults with an ID were recruited. Interviews were also conducted in

English and Spanish, which gave Spanish speakers the opportunity to participate. It was hypothesized that through a contextual model we would be able to see how positive supports, presence of meaning in life, meaning in caregiving, search for meaning, and aggression towards caregiver contribute to caretaker well-being. Secondly, it was predicted that caregiver appraisals, such as presence of meaning in life, meaning in caregiving, and search for meaning, would operate as mediating factors of well-being. Through our findings we hope to further advance this line of research to improve current interventions and programs designed to minimize caregiver burden and increase access to positive support systems.

CHAPTER II

LITERATURE REVIEW

Caregivers of Individuals with Intellectual Disability and Wellbeing

Caretakers are responsible for the care of individuals who are unable to function in an array of capacities and may require assistance with various ADL's and IADL's (e.g., bathing, eating, dressing, finances, making calls, setting up medical appointments, driving, and meal preparation; Kottorp, Bernspang, & Fisher, 2003). Yet, program developers have focused primarily in the delivery of services of care recipients and have historically neglected caregiver needs. For instance, in south Texas the majority of programs (e.g., home community-based services, Texas Home Living) offer residential services, behavioral support, specialized therapies, and nursing (Texas Department of Aging and Disability Services, 2015) to the care recipient. However, only respite services specifically and explicitly pertain to caregiver well-being (although the others may be quite relevant). More recently, efforts are being made by researchers and program developers to alleviate caregiver burden through community-based programming, hiring family members for caregiving practices, and promoting peer support groups (e.g., Heller & Caldwell, 2006). Nevertheless, gaps in the literature pertaining to caretaker needs continue to exist today (Perkins & LaMartin, 2012). In particular, such gaps are seen among ethnically diverse caregivers who are often forced to seek out informal support systems through community leaders, churches, and community support groups due to an array of multicultural factors (e.g., lack of

knowledge, mistrust, and unavailability of culturally appropriate services; Scharlach et al., 2006).

A vast majority of research has shown that caregivers of individuals with ID experience burden (e.g., Green, 2007; Wade et al., 1996); however, other research has found that caregivers of individuals with ID successfully adapt to their caregiver role (Weisz & Tomkins, 1996). Despite the incongruent findings within this line of research, it is essential to contemplate caregivers' distinctive experiences, adjustment, and psychological processes (Cummins, 2001; Wikler et al., 1981). In addition, it is imperative to further examine burden and well-being contextually through existing theoretical models (e.g., Resch, 2012).

Caregivers of individuals with ID are unique in that they tend to be the biological parents of the care-recipient (Wikler et al., 1981). Consequently, they are required to adapt and provide specialized care as early as the care-recipient is born, or at least from the time diagnosis is established. This is not necessarily the case for those caregivers where the care-recipient suddenly becomes ill or disabled, and where caregivers tend to be spouses, siblings, and children of the care-recipient (Wikler et al., 1981). In other words, caretakers of individuals with ID go through a different psychological and adjustment process compared to caregivers of individuals with dementia or traumatic brain injury. Wikler and colleagues (1981) examined opposing views on how caregivers adjust to becoming the caregiver of an individual with ID. The first view has been popular among scholars and stems from the belief that caregivers go through a "time-

bound grief." More specifically, caregivers go through stages of grief in the order of shock, despair, guilt, withdrawal, acceptance, and finally "adjustment".

A less popular perspective emphasizes a "chronic sorrow" in which even a parent who copes well will repeatedly experience intense grieving. Research has supported the latter approach, which showed that parents experience "chronic sorrow" rather than "time-bound" adjustment (Wikler et al., 1981). More explicitly, caregivers reported experiencing various periods of stress and sadness, and continuous rather than sporadic feelings of "chronic sorrow" (Wikler et al., 1981). Further, Baker and colleagues (1997) suggest that caregiver experiences are contingent upon care-recipients' age of diagnosis and social development (e.g., elementary school, high school).

Research has shown that burden and time demands for caring for an individual with ID varies across the life span of the individual (Haveman, Van Berkum, Reijnders, & Heller, 1997). Blacher (2001) suggests that even though there is extant literature on the different transitions individuals with ID experience, there is little research on one of the most critical developmental stages, which occur from adolescence to adulthood (ages 18-26). During this period caregivers are faced with new challenges and barriers related to individual, family, and positive support systems, which may put individuals with ID at higher risk for behavioral and psychiatric disturbances.

Other researchers (e.g., Cheseldine & Jeffree, 1981) suggest that during this social developmental stage caregivers come to the realization that care-recipients are not able to participate in age-appropriate activities and that caregiving responsibilities may increase (Blacher, 2001). Further, Blacher (2001) explains that coping strategies such as

"one day at a time" are no longer effective during this period, and caregivers are forced to become more engaged in future planning and the process of transitioning. Research has also shown that caregivers of young adults feel less supported, isolated, and are in more need of prolonged services when compared to caregivers of children and adolescents (Suelzle & Keenan, 1981). The developmental stage from adolescence to young adult is one of the most stressful periods for caregivers, due to the lack of positive supports post-high school and cultural expectations of caretaker involvement (Blacher, 2001; Ferguson, Ferguson, & Jones, 1988; Haveman et al., 1997).

Caregiver Burden

Caregivers are required to engage in laborious tasks that require specialized care and time. More explicitly, taking care of an individual with ID requires extended hours of care during the day, specialized knowledge, contacting multiple medical delivery systems, and support from professionals, friends, and relatives (Baker et al., 1997; Green, 2007). Baker and colleagues (1997) posit that caregivers become mainly responsible for making specific adaptations such as considering the child's behavior and needs, behavior management, delivery of learning experiences, and constant interactions with education and medical professionals. As a result, caregivers' life styles are greatly impacted to the extent where family activities are disrupted, social activities are restricted, employment opportunities are lost, and financial burden increases (Donenberg & Baker, 1993; Gunn & Berry, 1987; Parish, Seltzer, Greenberg, & Floyd, 2004; Rodrigue, Morgan, & Geffken, 1990; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). Baker and colleagues (1997) suggest that family stress varies depending on the care-

recipient's development; however, that it remains constant throughout the caregiving experience. Further, research has shown that caretakers are more prone to depression, are at higher risk for alcohol dependency, have lower rates of unemployment, and lower quality of physical and mental health compared to non-caregivers (Seltzer et al., 2001; Wade et al., 1996).

Caregiver burden risk factors include care recipients' comorbidity of psychiatric disorders, ethnic background, social economic status, and age of caregiver (e.g., Eisenhower & Blacher, 2006; Haley & Perkins, 2004; Irazabal et al., 2012; Knight, Silverstein, McCallum, & Fox, 2000; Valle, Yamada, & Barrio, 2004). It is especially problematic when caregivers provide care to individuals with ID who exhibit behavioral problems and aggression toward caregivers (e.g., Erosa et al., 2010). Maes, Broekman, Dosen, and Nauts (2011) found that 62% of children and 86% of adults who were referred to community health centers had severe psychiatric or behavioral problems. Moreover, it has been shown that parental stress was higher in caregivers who provided care for an individual with autism and severe ID, compared to those caregivers who provided care for individuals with cystic fibrosis (Bouma & Schmeitzer, 1990). Additional factors contributing to caregiver burden were low levels of functioning, lower intelligence quotient, and number of children in the household (Eisenhower & Blacher, 2006; Green, 2007; Irazabal et al., 2012). Green (2007) also found that perceived stigma and social-cultural restraint rather than emotional distress was associated with caregiver burden (Green, 2007).

Positive and Protective Factors

Although extant literature has demonstrated that caregivers of individuals with ID experience higher levels of burden compared to non-caregivers (e.g., Lin et al., 2009), it is equally important to examine positive and protective factors among caregivers of individuals with ID (Baker et al., 1997). Earlier research has primarily focused on caregiver burden, which resulted in limited scrutiny in the area of positive factors associated with caregiver well-being (Hastings, Allen, McDermott, & Still, 2002; Helff & Glidden, 1998; Scorgie & Sobsey, 2000; Trute, Benzies, Worthington, Reddon, & Moore, 2010). Nevertheless, more recently there has been a shift in mainstream research, and scholars are beginning to formulate research questions about the positive experiences of caregivers of individuals with ID and how these are related to coping mechanisms (Hastings & Taunt, 2002; Helff & Glidden, 1998).

Helff and Glidden (1998) reviewed the available literature on positive adjustment of caregivers of children with ID from 1970 through the 1990s. They found that there was a change in the way researchers viewed caregiver adjustment. The most salient changes were noted in a decrease in topics related to global negativity and an increase in writing about positive adjustments in discussion sections. This shift has led other investigators to continue with this line of study and many have uncovered a myriad of factors related to positive emotion, views, coping, and well-being.

Hastings and Taunt (2002), for example, examined various studies on positive perceptions in families with children with developmental disabilities. They found that most family members reported an array of positive perceptions and experiences.

Although family members did experience more distress than families of non-disabled children, they did not report less positive perceptions. They concluded that many families are able to adapt well to caregiving challenges, and positive perceptions and feelings may be crucial to the development of intervention goals designed for families of children with disabilities.

Similarly, Hastings and colleagues (2002) found that among mothers of children with ID, reframing coping strategies was a predictor of positive perceptions on caregiving. Interestingly, they discovered that those mothers who reported higher levels of caregiving demands also reported more positive views about themselves (e.g., personal growth). Hastings and colleagues (2002) suggest that raising a child with a more severe disability may boost feelings of self-efficacy, which can lead to personal growth and maturity. Consistent with these findings, other researchers have found that caregivers are able to experience positive emotions by developing personal and emotional growth. (Scorgie & Sobsey, 2000). Further, caregiving experiences and positive appraisals can produce changes in philosophical and spiritual values and positively contribute to caregiver and family adjustment (Affleck, Allen, Tennen, McGrade, & Ratzan, 1985; Heller, Miller, & Factor, 1997; Resch et al., 2012; Scorgie & Sobsey, 2000; Trute et al., 2010).

Theoretical Framework

Due to the complexity of the caregiving experience there are multiple factors that contribute to caregiver well-being and burden (Raina et al., 2004). Studies have demonstrated that caretakers adapt to their caregiving situation, which has led to

dichotomous findings regarding the amount of strain and positive emotions caregivers of individuals with ID experience. As a result, researchers have started to focus on contextualizing constructs that may be determinants of caregiver adjustment. Further, in their attempt to uncover the dynamic process of caregiver well-being and caregiver strain, scholars have designed an array of contextual models stemming from theoretical frameworks in order to advance this line of research (Resch et al., 2012; Thompson, Gil, Abrams, & Philips, 1992; Wallander & Varni, 1998).

Lazarus and Launier (1978) were among the first to introduce a model designed to address coping and stress in the general population. In their theoretical framework they introduced two processes, cognitive appraisals and coping, which they suggested served as mediators between stressful person-environment transactions and their immediate outcomes. In their coping-stress model they included personal characteristics (e.g., age, education) and stressors (patient functional status, patient memory, and behavior problems), and mediating conditions such as individual's personal resources (e.g., physical, social, financial) and individual's coping (e.g., problem focused, emotion focused, and relationship focused). The last element of the model is composed by two outcome variables, which include maladaptation (e.g., depression) and bonadaptation (satisfaction).

One of the most prominent coping-stress models intended to capture the caregiving experience was established by Pearlin and colleagues (1990), who posited that caregiver stress is a "stress process" that entails transactions between contextual factors leading to distress and interpersonal relationships that develop and change over

time. More explicitly, they identified in their contextual model the following components: background and context (e.g., demographic variables, care-recipient-caretaker relational history, family and network composition, and access to programing), primary stressors (e.g., caregiving demands pertaining to ADLs and IADLs, care-recipient problematic behavior and cognitive status, caregiving task overload, and relational deprivation), secondary stressors (e.g., personal-caretaker role conflict, financial stress, limited or lack of social life), and secondary-intrapsychic strains (e.g., self-esteem). Mediating factors served to explain questions such as "Why is it that some caregivers seem to fare better than others, though their life circumstances might not be easier?" The model identified coping (e.g., appraisals) and social support as mediating factors contributing to the strength of relationships within the model. Lastly, mental and physical health, and adjustment to social roles are used as indicators of well-being.

Pearlin and colleagues (1990) suggest that demographic characteristics such as gender, social economic status, and ethnicity lead to social inequality, which exacerbates caregiver stress. Accessibility to community programming is crucial, since it can provide an outlet for caregivers to be connected to a larger community and decrease isolation and alienation. Primary stressors such as problematic behavior result in challenges pertaining to "damage control" to prevent care-recipient self-harm or aggression toward others. Additionally, cognitive status is an important factor to consider, since it can have a negative impact on the existing caretaker-care-recipient relationship. Secondary stressors are equally important, which involve "role strains" and "intrapsychic strains." Role strains relate to difficulties managing multiple roles within the family unit, while

maintaining occupational roles. Intrapsychic strains pertain to the self-concept such as loss of self, role captivity, mastery, and gain. Caregivers may lose their personal identity as they become overly engaged in their caregiving role. Feelings of being captive may develop, as the caregiver feels compelled to engage in the caregiver role without fully having the desire to do so. Conversely, factors such as competence and mastery may result in positive outcomes such as inner-growth.

Previous theoretical conceptualizations have served as a foundation to the current literary works, and have led to development of models that have been widely cited in the caregiving literature. Thompson and colleagues (1992) proposed the Transactional Stress and Coping model deriving from an ecological systems theory, which has been mainly applied to individuals who suffer from a medical illness and their families (e.g., Hocking & Lochman, 2005; Laubmeier, Zakowski, & Bair, 2004). They posited that once individuals are faced with stressful events (e.g., illness), individuals and their families go through an adaptation process. They suggest that adapting to the illness is not a direct process, but rather, it is mediated by transactions and exchanges between illness parameters, demographic parameters, and child and maternal "adaptational" processes.

In particular, the model is composed of the following features: meditational processes such as cognitive processes (appraisal-stress, daily hassles, illness tasks, efficacy, expectations), methods of coping (palliative, adaptive), and family functioning (supportive, conflicted, controlling), illness parameters (type, complication, frequency of painful episodes), generic parameters (gender, age, social economic status), and maternal and child adjustment as outcome variables. This model has been criticized by Wallander

and Varni (1998); they argue that it is limited when it comes to making generic conclusions, since it has primarily been used with individuals who suffer from sickle cell disease and cystic fibrosis. Further, they explain that the utilization of this model restricts researchers in a wide range of variables and applications.

The conceptual model of child adjustment to pediatric chronic physical disorders was proposed by Wallander and Varni, and it was intended to be more generic compared to other models by allowing researchers to make a wide range of applications (Wallander & Varni, 1998). They argue that a child's disability becomes a chronic strain for both the child and the parent, and that their model is able to identify risk and resistance factors. This model comprises of the following factors: disease/disability (e.g., severity, visibility, brain damage, cognitive functioning), functional dependence (e.g., hygiene, ambulation, communication), psychosocial stress (e.g., handicap-related problems, daily hassles, major life events), stress processing (e.g., cognitive appraisal, coping strategies), personal factors (e.g., temperament, competence, effectance motivation, problem solving ability), social-ecological factors (e.g., family environment, family members, adjustment, social support) and adjustment/adaptation (e.g., mental, social, physical; Wallander & Varni, 1998).

More recently, other researchers have continued to develop multidimensional models with modifications and extensions to existing models to further advance theory and examine new constructs within contextual conceptualizations (e.g., Elliott & Mullins, 2004; Raina et al., 2004; Resch et al., 2012). Elliott and Mullins (2004) introduced the dynamic process model of well-being arguing that adjustment should be

examined throughout the lifespan since individuals with a chronic illness/disability and their families develop in terms of age, relationships, and technological advances. Stress is not a central element of this model; instead, it emphasizes the importance of phenomenological appraisals and personal experiences of events and how these are shaped by environmental factors. In addition, the model considers an array of social, institutional, and service related issues such as school placement and support from public health programs. Variables in the model include enduring characteristics and individual differences and social and environmental characteristics. Phenomenological and appraisal processes serve as mediating components and variables pertaining to psychological and physical health—which have been used as indicators of well-being in the current literature (e.g., Diener & Chan, 2011)—function as outcome variables.

Recently, Resch and colleagues (2012) examined well-being among parents of children with disabilities using the dynamic process model of well-being. They examined child severity, parent social problem solving abilities, resources and environmental/social characteristics, and appraisals of threat and growth. Their outcome variables consisted of parent physical and emotional well-being, life satisfaction, and family satisfaction. They found that caregiver appraisals (e.g., personal growth), problem solving skills and environmental/social supports contributed to caregiver well-being. Further, the results of this study echoed previous findings showing that disability severity and parent's education level did not contribute significantly to parental well-being.

Care-Recipient Characteristics: Care-Recipient Aggression

Aggression among individuals with disabilities has been studied in an array of contexts and settings (e.g. Crocker et al., 2006; Gates, Fitzwater, & Succop, 2005; Hensel, Lunsky, & Dewa, 2012; McClintock et al., 2003; Mikton, Maguire, & Shakespear, 2014). Predominately this line of the research has focused on incidence, type of aggressive behaviors, risk makers, and interventions (e.g., Cooney & Howard, 1995; Gates et al., 2005; Kilburn, 1996; Ryden, Bossenmaier, & McLachlan, 1991; Wanless & Jahoda, 2002). While other researchers have specifically examined aggression toward caregivers who provide care for individuals with disabilities related to psychiatric disorders, dementia, and ID (Cahill & Shapiro, 1993; Gates, Fitzwater, & Meyer, 1999; Menckel, Carter, & Viitasara, 2000; O'Leary, Jiryngi, & Sedler, 2005; Straznickas, Mcniel, & Binder, 1993). Nevertheless, scholars have neglected to incorporate this variable in their elaborated contextual models of well-being (e.g., Elliott & Mullins, 2004; Noojin & Wallander, 1997; Raina et al., 2004; Resch et al., 2012). Although it is crucial to investigate aggression towards caregivers in terms of etiology, incidence, and type, it should also be examined within contextual models of caregiver well-being to further understand its contribution.

Caretakers report that individuals with an ID explicitly engage in different types of aggression such as aggression toward others, property destruction, stereotypy, self-injurious behavior, and sexual behavior (Crocker et al., 2006; Lundqvist, 2013; Ryden et al., 1991; Smith & Matson, 2010; Zeller et al., 2009). Multiple studies have revealed that comorbidity with psychiatric disorders (e.g., autism spectrum disorder, anxiety,

19

epilepsy), night sleep disturbances, sensory hypersensitivity, motor impairment, communication dysfunction, and psychosis have been associated with higher incidence of aggressive acts among individuals with ID (Crocker et al., 2006; Holden & Gitlesen, 2003; Lundqvist, 2013; McClintock et al., 2003; Smith & Matson, 2010). Interestingly, research has also indicated that individuals with ID who were taking psychotropic medication showed higher levels of aggression (e.g., Lundqvist, 2013; Ryden et al., 1991). Further, contradicting findings have been found in relation to gender differences in aggression among individuals with ID (Cooper et al., 2009; Crocker et al., 2006).

Research on aggression among individuals with ID can facilitate recognition of risk makers and triggers of acts of aggression within residential settings (Zeller et al., 2009). Erosa and colleagues (2010) examined caregivers' experiences with aggression and found that caregivers in this study had been exposed to at least one experience of verbal or physical abuse. Additionally, they found that 46% reported being "yelled at or insulted", 13% received "threats to hit," and 13% reported being hit by a perpetrator. The majority of the perpetrators were identified as care-recipients who were diagnosed with a severe disability. They also found that caregivers who experienced aggression had higher levels of depression, burden, and health complaints, compared to caregivers who did not report any type of abuse. Not surprisingly, caregivers who did not experience aggression reported higher levels of life satisfaction (Erosa et al., 2010).

Moreover, research has found high incidents of physical and verbal aggression among individuals with an ID, ranging from 61% up to 71% of the incidents directed towards caregivers (Strand, Benzein, & Saveman, 2004; Tenneij & Koot, 2008). Most of

20

these incidents were physical aggression that occurred in helping situations or when both the caregiver and care-recipient displayed aggression. In addition, these caregivers also reported that this type of aggression had affected them physically and emotionally and left them feeling powerless and inadequate (Strand et al., 2004; Tenneij & Koot, 2008). Aggressive behavior has shown to be significantly higher in family type residences and group homes compared to family homes and independent living settings (Crocker et al., 2006). Crocker and colleagues (2006) suggest that these finding can be attributed to an array of factors including undiagnosed medical problems, stress of victimization, and certain environmental factors.

Though various studies have demonstrated that caregivers of care-recipients displaying challenging behaviors are at higher risk for developing emotional and physical difficulties (e.g., Franz, Zeh, Schablon, Kunnert, & Nienhaus, 2010), other scholars have also shown that care-recipient maladaptive behaviors have weaker associations with caregiver stress compared to factors such as caregiver locus of control (Unwin & Deb, 2011). Currently there is a lack of consensus within researchers on how to study aggression among individuals with disability, which has made it even more challenging to make steady conclusions (Cooper et al., 2009; Crocker et al., 2006). Additional findings are needed so that researchers can aid program developers implement effective interventions and provide appropriate resources to prevent out of home placements and ameliorate caregiver burden (Tenneij & Koot, 2008).

Resources and Environment/Social Characteristics

Caregivers are faced with the task of providing extensive care along with a plethora of resources and supports to care recipients (Haveman et al., 1997; Heller, Hsieh, & Rowitz, 2000; Tsai & Wang, 2009). Research revealed that caregivers experience multiple community barriers and unmet needs, which have resulted in detrimental effects on caregiver well-being (e.g., Parish et al., 2004; Resch et al., 2010; Tsai & Wang, 2009). In addition, inadequate services and resources tend to hinder caregivers' ability to develop professionally and personally (Paris et al., 2004). Therefore, it is important to further examine barriers and social support systems among caretakers of individuals with ID within our contextual model.

As stated earlier, caregivers of individuals with ID typically provide care from the time the care-recipient is provided with a diagnosis and throughout their adulthood years (Haveman et al., 1997). Consequently, caretaker and care-recipient needs tend to change over time. Haveman and colleagues (1997) found that parents of individuals with ID go through a life cycle of needs. For instance, during the first years of the care-recipients' life (infancy to 9 years of age), caregivers reported that their primary needs consisted of emotional support, medical services, and therapeutic services for their children (e.g., speech, dietitian, and in-home respite). As the child enters the teenage years assistance is required with extracurricular activities, out-of-home respite on the weekends and holidays, and support from dentists. Thorough adulthood caregivers reported that they required support with out-of-home placements, advice with future planning, transportation, and physicians. In all three stages, it was imperative for parents

22

to receive continuous support with developmental and medical issues. Further, studies revealed that as caregivers get older they are less likely to have available resources, their social support networks are smaller, and their families are less cohesive, less expressive and, display more conflict (White & Hastings, 2004). Older caregivers were also most likely to be widows, less likely to accept help, and relied more often on spiritual supports (Hayden & Heller, 1997; White & Hastings, 2004). Nevertheless, younger caretakers reported more unmet needs, but scholars suggest that this could be due to having higher demands on the service delivery system (Hayden & Heller, 1997).

The current body of literature has been able to delineate a set of barriers and unmet needs by caregivers (e.g., Resch et al, 2010; Siklos & Kerns, 2006; Worcester, Nesman, Mendez, & Keller 2008). More specifically, Worcester and colleagues (2008) discovered the following themes related to barriers and unmet needs: obtaining accurate and useful information, obtaining services and supports, financial burden, stress among members of the family, and community isolation. Likewise, Resch and colleagues (2010) also found that family caregivers of children with disabilities faced the following barriers: obtaining access to information and services, financial barriers to obtaining services, school and community inclusion, and family support.

Studies have shown that caregivers struggle to obtain information pertaining to services and care recipients' special needs, in particular, from medical professionals and social workers (Freedman & Boyer, 2000; Worcester et al., 2008). It has been reported that these professionals provide inadequate information, lacked knowledge, or were unresponsive (Freedman & Boyer, 2000; Worcester et al., 2008). Conversely, other

researchers found that caregivers reported feeling comfortable seeking social supports from teachers of special education at schools, teachers of rehabilitation training courses, and social services personnel (Tsai & Wang, 2009). Freedman and Boyer (2000) suggest that there should be advocacy to educate professionals, such as medical personnel, teachers, and social workers, about the needs of individuals with special needs. Moreover, a high percentage of caretakers (75%) identified the Internet as a primary source of information (Blackburn & Read, 2005; Worceser et al., 2008). Caregivers reported that they typically relied on the Internet for emailing, obtaining information about caring, ordering equipment, and shopping. Although the Internet can be a beneficial tool, access to web-linked computers and ability to search varied across caregivers (Worcester et al., 2008). For example, other caregivers reported not having sufficient time to engage in Internet searches and finding misleading information about their children's disability (Blackburn & Read, 2005).

Further, it has been found that caretakers and individuals with special needs at times are unable to receive appropriate services that met their needs (Freedman & Boyer, 2000; Worcester et al., 2008). Informal caregivers have reported that it was a "fight" to obtain services and information due to the lack of organization and communication between service providers (Resch et al., 2010). Research also revealed that many formal care providers (e.g., health aides, respite workers, nurses) lack training and experience in working with individuals with disabilities (Freedman & Boyer, 2000; Worcester et al., 2008). Informal caregivers also encounter systemic barriers such as restrictions in eligibility criteria (e.g., severity of diagnosis) and convoluted administrative regulations

(Freedman & Boyer, 2000). Services can have certain restrictions such as delayed reimbursements, reduction or termination of therapies, inability to choose a care provider, and inflexibility in the Medicaid system (Freedman & Boyer, 2000). These limitations can result in caregivers incurring additional expenses for medications, equipment, and supplies needed for activities of daily living (Freedman & Boyer, 2000; Parish et al., 2004). In addition, caregivers identify unmet needs in the areas of therapies (e.g., behavioral, physical, occupational) social recreational activities, and respite services (Freedman & Boyer, 2000; Grant & McGrath, 1990; Pruchno & McMullen, 2004).

Due to additional expenses related to care-recipient needs and inability to advance professionally, caregivers usually report financial strains (Parish et al., 2004; Resch et al., 2010; Winslow, 2003; Worcester et al., 2008). More explicitly, caregivers often have lower financial savings and fewer opportunities for employment compared to non-caregivers (Caldwell, 2008; Parish et al., 2004). Not surprisingly, caregivers who have external resources such as an education and high economic status have reported better sense of control and security over their children's future (Ben-Zur, Duvdevany, & Lury, 2005).

Although families of individuals with disabilities routinely acknowledge the importance of social and emotional support from friends and family members, this continues to be an unmet need (Siklos & Kerns, 2006). For instance, research has shown that care-recipient's disruptive behavior and caregiving roles led to higher marital discord and conflict between immediate family members (Resch et al., 2010; Worcester

et al., 2008). Caregivers also reported limited family gatherings and community outings, which resulted in minimum interactions with friends and family members, feelings of isolation, and often being forced to advocate for social inclusion (Freedman & Boyer, 2000; Resch et al., 2010; Worcester et al., 2008). Freedman and Boyer (2000) suggest that program developers should view an individual with a disability in a holistic manner so that additional support is provided to family members.

Culture-specific barriers have also been found within caregivers of color. Research has shown that they tend to report additional barriers such as lack of cultural specific services and knowledge due to language impediments (Dilworth-Anderson, Williams, & Gibson, 2002; Scharlach et al., 2006). They also reported distrust in formal services and higher use of natural supports (Dilworth-Anderson et al., 2002; Scharlach et al., 2006). It was found that they constantly use neighbors, family members, and friends for respite services, relied on religious organizations for social support, and referred to formal services as "too dangerous". Nevertheless, they express a great need for in-home respite services such as having someone to assist a few hours a day with cooking, activities of daily living, and transportation (Scharlach et al., 2006). Caregivers of color also tended to put more emphasis on care-recipient needs than their own needs even when they were directly asked about their own needs (Scharlach et al., 2006). Additionally, research revealed that they had higher levels of need of formal support systems and less satisfaction with services (Dilworth et al., 2002; Scharlach et al., 2006).

Although efforts have been made to improve programing for individuals with special needs and their families, caregivers continue to face multiple barriers at a

community level (Resch et al., 2010; Worcerster et al., 2008). Redmon and Richardson (2003) found that caregiver burden was mainly associated with services that were inadequate, uncoordinated, and hard-to-access. Caretakers also reported that most of their frustrations derived from administrative and political regulations. Ineffective service delivery systems can lead to detrimental effects on caregiver well-being; therefore, it is crucial for program developers to find alternative methods to reduce barriers and increase resources (Caldwell, 2008; Hayden & Goldman, 1997).

Conversely, research has found that when caregivers engage in effective programing they are more likely to report greater satisfaction with services, improved finances, fewer unmet needs, increased self-efficacy, lower levels of burden, larger social networks, and less out-of-home placements (White & Hastings, 2004). In addition, social services and support has been shown to improve the overall health of caregivers of individuals with ID (Davis & Gavidia-Payne, 2009; Hayden & Goldman, 1996; Tsai & Wang, 2009). Scholars suggest that caregivers of individuals with special needs require flexible and responsive services in order to help them adapt and cope more effectively (Redmond & Richardson, 2003).

Caregiver Appraisals: Meaning in Life and Meaning in Caregiving

Meaning in life is a popular concept within the realm of positive psychology, and it has been widely studied in relation to well-being. Research has revealed that meaning in life is related to higher levels of psychological and emotional well-being (e.g., Ganellen & Blaney, 1984; Owens, Steger, Whitesell, & Herrera, 2009; Steger & Frazier, 2005; Steger, Kashdan, Sullivan, & Lorentz, 2008). Further, it has been suggested that

meaning and search for meaning in life are essential components in the development of human kind (Frankl, 1985). Caregiver experiences are complex; however, little is known about meaning in life among caregivers. More specifically, to our knowledge there is no current study that has examined meaning among caregivers of individuals with an ID. Therefore, this is an area of study that requires scrutiny from scholars, given that it can shed light to both theoretical and clinical applications in caregiver research (Farran et al., 1991; Kramer, 1997).

Meaning in life. Victor Frankl is one of the founders of the concept of meaning in life and search for meaning (Frankl, 1985). He is also the pioneer of logotherapy, The Purpose in Life Test, and concepts such as "existential neurosis" (Crumbaugh & Maholick, 1964; Frankl, 1985, 2005). His experiences as a Nazi concentration camp captive led to his literary works in meaning in life as a coping mechanism (Frankl, 1985). More specifically, Frankl (1985) postulated that after experiencing adverse life events (e.g., suffering, death, privation) an individual is able to cope through finding deeper meaning in life, which is founded by fate and spiritual freedom. He also suggested that tragedies and hopeless situations could be transformed into triumphs through meaning.

Meaning in life varies across individuals, time, belief systems, and develops throughout an individual's life cycle, but it does not cease (Frankl, 1985; Reker & Wong, 1988). The complexity of this concept has resulted in a variety of definitions among scholars (King, Hicks, Krull, & Gaiso, 2006; Steger, Frazier, Oishi, & Kaler, 2006). For instance, deriving from Frankl's theoretical views, Crumbaugh and Maholick

(1964) defined meaning in life as "the ontological significance of life from the point of view of the experiencing individual", and used "purpose" and meaning in life interchangeably (p. 201). Similarly, other researchers have referred to meaning as the feeling that one's life is coherent (Battista & Almond, 1973; Reker & Wong, 1988), as "goal directedness" or "purposefulness", among others (as cited in Steger et al., 2006). More recently, King and colleagues (2006) suggest that researchers have primarily relied on individuals' "intuitive understanding of meaning," and describe meaning in life as "lives may be experienced as meaningful when they are felt to have significance beyond trivial or momentary, to have purpose, or to have a coherence that transcends chaos" (p. 180).

Despite the various definitions that currently exist in the literature, scholars have come to the consensus that meaning in life is crucial for an individual's well-being (Steger et al., 2006). Frankl (1985) suggested that when a person experiences "existential vacuums," which refers to feeling empty and meaningless, the individual becomes vulnerable to "neurosis", such as depression, aggression, and addiction. Similarly, Maddi (1967) studied "existential neurosis" which is a function of "premorbidity" (e.g., personality characteristics) and stress. "Existential neurosis" comprises of cognitive, affective and "actional" components. More specifically, "meaningless" leads to the inability to find truth, importance, usefulness, or interest in one's present and future (cognitive component). In addition, it leads to a state of "blandness" and boredom with varied periods of depression (affective component), and to low-moderate levels of selectivity in actions ("actional" component).

Harlow, Newcomb, and Bentler (1986) examined lack of purpose through their theoretical structural model of five constructs: depression, self-derogation, purpose-of-life, substance use, and suicidal ideation. They found that those who had lower levels of purpose in life tended to be more depressed, engaged in more self-derogation statements, and were at higher risk of suicide and substance abuse. Similarly, other researchers have shown that lack of meaning in life has been associated with negative aspects of well-being such as negative health outcomes, higher levels of depression, and posttraumatic stress disorder (e.g., Ganellen & Blaney, 1984; Owens et al., 2009; Steger & Frazier, 2005; Steger et al., 2008). Further, Reker, Peacock, & Wong (1987) found that the "existential vacuums" (meaningless and emptiness) predicted psychological and physical well-being.

On the contrary, Yalom (1980) suggested that when an individual has a sense of meaning in life it leads to strong religious beliefs, self-transcendent values, membership in groups, dedication to a cause, and defined life-goals (as cited in Zika & Chamberlain, 1992). Moreover, research has found that meaning in life tends to have stronger associations with positive aspects of well-being, such as optimism, self-esteem, career decisions and meaning, efficacy, and positive adjustments to illnesses (e.g., Ho, Cheung, & Cheung, 2010; Scannell, Allen, & Burton, 2002; Steger & Dik, 2009; Zika & Chamberlain, 1992). Meaning in life has also been associated with personal commitment and personality factors such as curiosity, sense of coherence, and hardiness (Antonovsky, 1979; Kashdan & Steger, 2007; Kobasa, 1979; Lazarus & DeLongis, 1983; Steger et al., 2008). Hardiness, in particular, has been used to describe individuals

who are able to maintain psychological well-being after experiencing adversity (Kobasa, 1979).

Although meaning in life has been widely studied, search for meaning is a more complex and enigmatic construct that has been given less focus (Frankl, 1985; Steger et al., 2008). Consequently, scholars have opposing views about its functionality and psychological process. Frankl (1985) postulated that search for meaning was healthy and naturally occurring. In addition, he viewed search for meaning as a way to explore new possibilities and challenges while making sense of one's experience. Similar to meaning in life, search for meaning varies in degree across individuals (Steger et al., 2008); however, scholars have studied meaning in life and search for meaning as divergent constructs (Steger & Dik, 2009). They contend that presence of meaning refers to what other scholars have referred to as "meaning in life" (e.g., feeling one's life matters) (King et al., 2006), whereas search for meaning is "intensity and activity of people's desire and efforts to establish and/or augment their understanding of meaning, significance, and purpose of their lives" (Steger et al., 2008, p. 200).

Steger and colleagues (2008) explored presence of meaning and meaning in life and concluded that these are independent psychological processes. Research has shown that search for meaning does not indicate absence of meaning; however, those who lack meaning and tend to search for meaning will display lower levels of well-being (Steger et al., 2008). Search for meaning has both negative and positive implications. Studies have shown that it is related to negative thinking, feelings of little control over their environment, lack of self-acceptance, anxiety, lack of autonomy, rumination on past

events, feelings of helplessness, and self and interpersonal dissatisfaction. On the other hand, it was also found to strengthen associations between life satisfaction and meaning in life. In addition, search for meaning has been shown to be associated with personal growth, purpose, openness, drive, curiosity, receptiveness and inquisitiveness. Steger, Oishi, and Kesebir (2011) note that when an individual has experienced trauma (e.g., sexual abuse, bereavement, strokes) presence and search for meaning are processed differently. They found that those who encountered these types of adversities tend to show higher levels of distress when they tried to search for meaning, in particular, when they were not able find meaning, and tried to find meaning in the event rather than life in general.

Meaning in life and search for meaning are considered essential for overall well-being (e.g., Frankl, 1985; Steger et al., 2008). Psychological interventions could potentially incorporate existential conceptualizations to alleviate burden among caregivers of individuals with ID (Krause, 2004; Schulenberg, Hutzell, Nassif, & Rogina, 2008). Frankl (1985) posits that logotherapy is future oriented, focuses on introspection, and encourages finding and searching for meaning. More explicitly, logotherapy suggests that meaning in life is found through deeds, experiencing something or encountering someone, and attitudes towards adversity. Logotherapy has been examined in different settings and with different populations (e.g., Frankl, 2005; Frankl, 2014; Guttmann, 1996; Melton & Schulenberg, 2007; Reker, 1994; Schulenberg, 2003; Schulenberg et al., 2008); however, more research is necessary to fully understand how it may contribute to caregiving experiences.

Meaning in caregiving. Previous caregiver research has mainly focused on the stress/coping paradigm, which focuses on negative aspects of caregiving and has neglected positive aspects (Farran, 1997; George & Gwyther, 1986; Kramer, 1997). Recently, this line of research has attended to the effects of meaning in caregiving on well-being (e.g., Butcher & Buckwalter, 2002). Additionally, through qualitative methods various themes have emerged in respect to existentialism, such as meaning in caregiving (Farran et al., 1991). Meaning in caregiving can serve as an alternative method to improve current interventions that focus on decreasing caregiver stress and improving well-being (Levine et al., 1984).

Levine and colleagues (1984) were among the first to promote a greater recognition of existentialism within the caregiver experience. The caregiver experience was described as an existential crisis "par excellence." Similar to someone in captivity (e.g., prison, concentration camp) caregivers are faced with making meaning of their experience, environment, and situation. Caretakers are capable of discovering meaning as they engage in the difficult task of caring for someone with a disability. Moreover, Kramer (1993) and Farran (1997) suggest that unlike stress/coping models, existentialism focuses on caregiver values, moral decisions, and their ability to find meaning by transforming their current situation. Therefore, existential aspects of caregiving could be further examined and utilized to inform current conceptual frameworks.

Many scholars have studied positive aspects in caregiving and find that these involve personal growth, purpose in life, autonomy, environmental mastery, self-

acceptance, pride, warmth, pleasure, life satisfaction, and meaning in caregiving (Archbold, 1983; Farran et al., 1991; Kinney, Stephens, Franks, & Norris, 1995; Lawton et al., 1991; Pinquart & Sorensen, 2004; Reece, Walz, & Hageboeck; 1983; Ryff, 1989). In particular, greater meaning in caregiving has been associated in theoretically consistent directions with depression, gratification, satisfaction, and physical health (Butcher & Buckwalter, 2002; Kinney & Stephens, 1989; Noonan, Tennstedt, & Rebelsky, 1997). Further, it has been found that caregivers are able to find meaning through cherished memories, spirituality, enjoying the present, and seeing caregiving as an "act of love" and part of family values (Butcher & Buckwalter, 2002; Sterritt & Pokorny, 1998).

Farran and colleagues (1991; 1999) have made major contributions in respect to meaning in caregiving, conceptually and psychometrically. Through qualitative analyses they found that caregivers reported existential themes when they were asked about their caregiving experiences. More specifically, Farran and colleagues (1991) found that 70% of caregivers were active in making choices about their attitudes toward caregiving and caregiving issues (e.g., using humor). Further, 90% reported that they valued the relationships they had with care recipients and found satisfaction when care recipients displayed appreciation. Caregivers also expressed valued feelings of confidence when providing care. Other researchers have also made advancements in this line of research by examining meaning in caregiving among diverse populations (e.g., Lee, Farran, Tripp-Reimer, & Sadler, 2003; Lim et al., 1996; Sterritt & Pokorny, 1998).

Farran and colleagues (1991) suggest that meaning in caregiving operates through personal choices about life and caregiving, positive values in respect to the caregiving experience and search for provisional and ultimate meaning. Moreover, they introduced an interactive model of finding meaning through caregiving with the following components: critical antecedents of caregiving (person creates meaning by making developmental choices, values provide basis for meaning, each person has responsibility for right action and conduct, provision and ultimate meaning exist), stages of caregiving (becoming aware of troubling symptoms, obtaining and acknowledging this diagnosis, assuming caregiving responsibilities: caregiving tasks, managing personal abilities), responses to caregiving (valuing positive aspects of relationships and caregiving, making personal choices about life and caregiving, searching for provisional meaning, searching for ultimate meaning), and potential caregiving outcomes (finding good and meaning through caregiving, or absence of good and meaning from caregiving, despair and hopelessness). These theoretical advancements have led to the development of measures in meaning in caregiving (Farran et al., 1999). This instrument consists of two subscales, which assess meaning on a daily basis, and philosophical, religious, and spiritual beliefs in respect to caregiving. Farran and colleagues (1999) found that provisional meaning subscale (e.g., meaning on a daily basis) moderated levels of depression and role strain.

Meaning in caregiving is an important factor to incorporate in contextual models of caregiver well-being. They can be useful at advancing current interventions used to improve caregiver quality of life and to have a better understanding of the unique

caregiver role (Farran et al., 1991; Kramer, 1997). In addition, it can help us decipher the enigma of "why" and "how" some caregivers are able to overcome caregiver burden and enjoy their lives, while others experience high levels of distress (Farran et al., 1999). It is important to note that meaning in caregiving is a complex concept with emotional and cognitive components that operate through searching and finding meaning (Noonan et al., 1997). Although various efforts have been made to have a better understanding of meaning in caregiving, there are a few limitations in the current literature worth noting. For instance, current measures of meaning in caregiving solely pertain to caregivers of individuals who have acquired a disability (e.g., Farran et al., 1999), and exclude caretakers of individuals with an ID. Moreover, current assessments assume that caregivers' religious and spiritual beliefs originate from a Judeo-Christian belief system (e.g., Farran et al., 1999). Moreover, Levine and colleagues (1984) suggests that service delivery providers and caregivers may have different conceptualizations on meaning in caregiving. Consequently, there is a lack of understanding on how service providers can support caregivers in stress reduction and coping skills (Levine et al., 1984). However, meaning in caregiving may provide important information that can be used to improve current interventions for caregivers (Farran et al., 1991; Levine et al., 1984).

The Current Study

The vast majority of research on caregiving has used disability interchangeably to describe multiple diagnoses (e.g., dementia, physical disability, and developmental disorders) and has focused predominately on parent-child caregiving relationships (e.g., Erosa et al., 2010; Resch et al., 2012). In the current study, we collected data from

36

caregivers of both children and adults whose disability was solely pertaining to ID. Due to innovative medical advancements, individuals with ID are outliving their biological parents, consequently close family members or non-relatives become the primary caregivers (Patja, Livanainen, Vesala, Oksanen, & Ruoppila, 2000). Therefore, we included relative and non-relative caregivers in our sample. Lastly, we collected data from Latino caregivers, since little is known about the caregiver needs and experiences of Latinos, yet this is one of the fastest growing diverse groups in the United States (U.S Census Bureau, 2010).

This study examined several important predictors and mediators that can be construed within the dynamic model of caregiver adjustment. In particular, environmental resources and care-recipient aggression are construed as critical predictor variables, consistent with prior study of barriers experienced by caregivers (Resch et al., 2012) and care-recipient behavioral problems (Erosa et al., 2010). The impact of these variables may likely be mediated by important caregiver cognitive appraisals of personal meaning. To our knowledge, this was the first study to examine meaning as a mediating variable in the prediction of caregiver adjustment. More explicitly, we examined a contextual model that included care-recipient characteristics (e.g., aggression toward caregivers), resources and environmental/social characteristics (e.g., financial, social, resources), caregiver appraisals (e.g., meaning in life, meaning in caregiving) in the prediction of caretaker well-being (mental and physical health composite scores).

CHAPTER III

METHOD

The study was approved by the Texas A&M University Institutional Review Board. A research team collaborated in selecting the measures, translating the materials, and in collecting informed consent from and administering the measures to consenting individuals.

Participants

The majority of participants were recruited from agencies that provided home and community-based services (HCBS) from a Medicaid waiver program administered by the Texas Department of Aging and Disability Services (DADS) in the Houston metropolitan area. It is important to note that a few caregivers were not part of the HCBS program and paid privately for day habilitation services at some of these agencies. For the purposes of this study a caregiver was defined as an individual over the age of 18 who provided formal or informal care to an individual with an ID at their residence or day habilitation program.

The total sample consists of 97 caregivers of individuals with an ID. This includes 71 women and 26 men (M_{age} = 53; age range: 21 to 81). Participants were from ethnically diverse backgrounds (75% Hispanic, 10% African American, 9% Caucasian, 1% Asian, 2% Other, and 2% did not report), born in different countries (46% Mexico, 43% United States, 7% El Salvador, 1% Philippines, 1% Venezuela, 1% Kenya, 1% did not report), and spoke English (45%) and Spanish (55%). The majority of the caregivers

reported that their highest level of education was high school (21%), were unemployed (69%), and married (55%). Participant's monthly income ranged from zero to $6,000.00 dollars annually ($M_{income} = 1451.48$, $SD = 1335.99$). Most caregivers reported that they were not receiving any type of government assistance for themselves (78%) and that they had never received mental health services (84%). The sample was composed of formal caretakers (67% host companion caregivers, 20% supported home living, 2% day habilitation, 7% other residential care) and informal caretakers (3% unpaid), and included relatives (52% mothers, 7% fathers, and 12% other relatives) and non-relatives (29%) of care recipients. However, it is important to note that the majority of the caretakers who became host companion caregivers were in the past informal caregivers who later became eligible to receive compensation for the care they provide through the HCBS program.

Materials

      Face-to-face interview. An interview was conducted in order to assess constructs similar to those described in the dynamic process model of well-Being (Elliott & Mullins, 2004). These included measures of environmental characteristics, caregiver and care-recipient characteristics, appraisal processes, and caregiver well-being. The research team translated measures that were not available in Spanish and other protocol materials used during recruitment and interviews. A bilingual (English-Spanish speaker) researcher was selected per Institutional review board standards to verify translation of documentation.

The Resources and Environment/Social Supports Questionnaire. The

Resources and Environment/Social Supports Questionnaire **(RESS-Q)** was used to

measure environmental characteristics. This scale was developed to assess specific

concerns associated with resources and environmental/social supports available to the

caregiver (Resch et al., 2012). The items were developed based on feedback from

parents of children with intellectual disabilities, researchers, and from theoretical and

empirical evidence on barriers experienced by those who care for individuals with

intellectual disabilities (e.g., Beckman, 2002; Resch et al., 2010; Worcester et al., 2008).

The scale consists of 16 items and it uses a 5-point Likert scale (1 = mostly disagree to 5

= mostly agree). Total scores range from 16 to 80. Higher scores reflect an appropriate

match between family needs and available environmental and social supports. Some of

the questions include "Important information related to the needs of the person I take

care of is easy to obtain and understand" and "I am pleased with my social life and the

number of opportunities I have to spend with friends and neighbors" (p. 64). Items were

modified to be suitable for formal and informal caregivers recruited for this study. Resch

and colleagues (2012) reported an acceptable internal consistency coefficient ($\alpha = .79$),

and our current data reached similar results ($\alpha = .76$) with our sample.

      The Ryden Aggression Scale. Care-recipient characteristics were identified as

aggression towards caregiver. The Ryden Aggression Scale (RAS; Ryden, 1988) was

used to assess aggression toward caregivers. The scale was developed from Lanza's

(1983) model of aggression, which focuses on innate origins of aggression with those

that emphasize environmental influences. There are three subscales, physical aggressive

behavior (PAB), verbally aggressive behavior (VAB), and sexually aggressive behavior (SAB). The instrument contains 25 items and the caregiver responds to each with a Likert-type rating (ranging from "never" = 0 to "one or more times" = 5) to indicate the occurrence of a specific behavior (e.g., pushing/shoving). Ryden (1988) reported an overall internal consistency reliability of .88 for the entire scale, .84 for PAB subscale, .90 for the VAB subscale, and .74 for SAB subscale. This instrument has been widely used in the research of caregivers both in outpatient and inpatient settings (e.g., Chen, Ryden, Feldt, Savik, 2000; Hamel et al., 1990). Our data showed an internal consistency coefficient of .94 for the entire scale.

Meaning in Life Questionnaire. To assess meaning in life we used the Meaning in Life Questionnaire (MLQ) developed by Steger et al. (2006). The measure has 10 items that are rated on a 7 point Likert scale (1 = absolutely true to 7 = absolutely untrue). This measure was developed to assess two dimensions of meaning in life. The first dimension is the presence of meaning, which reflects how respondents feel their lives have meaning. The second dimension is entitled search for meaning and it measures how engaged and motivated respondents are in finding meaning or to deepen their understanding of meaning in their lives. Steger et al. (2006) report acceptable reliability alpha coefficients for both presence of meaning (.86) and search of meaning (.92). Further, they found that compared to other similar scales the Meaning in Life Questionnaire showed to be a better and more efficient measure of meaning in life (e.g., no item overlap with distress measures, a stable factor, better discriminant validity, and briefer format; Steger et al., 2006). In the current study, the presence of meaning had an

internal consistency coefficient of .70 and search for meaning had an internal consistency coefficient of .88.

Meaning in Caregiving Scale. Meaning in caregiving was assessed with the Provision Meaning Scale, which is a subscale of the Meaning in Caregiving Scale (Farran et al., 1991; Farran et al., 1999). We decided to select 8 of the 19 items from the Provision Meaning subscale for the following reasons: 1) to avoid item overlap between the two meaning scales, 2) due to time restrain, and 3) to decrease participant burden. The subscale was designed to assess day-to-day meaning in caregiving using a 5-point Likert scale (5 = strongly agree to 1 = strongly disagree). Farran et al. (1991) explained that the scale consists of three qualitative themes that focus on caregivers' values in relation to positive aspects about life and caregiving, personal choices, and the means by which caregivers find small pleasures in their current situation. Provisional meaning refers to short-term or transitory experiences that give meaning to life. It can be found through day-to-day tasks and relationships (Farran et al., 1999). Sample items are as follows: "Caring for this person gives my life a purpose and a sense of meaning" and "Caregiving has helped me learn new things about myself" (Farran et al., 1999, p. 1117). Farran and colleagues (1999) report acceptable internal consistency ($\alpha = .88$) and test retest reliability (.85). Our data showed an internal consistency of .78 for the 8 items in the Provisional Meaning subscale.

Short Form Health Questionnaire-12. Caregiver well-being will be examined through psychological adjustment and physical health. Physical and emotional well-being was measured through the Short Form Health Questionnaire-12 (SF-12; Ware,

Kosinski, & Keller, 1996). The SF-12 features two composite scales that reflect quality of life: The Mental Component Summary (MCS) and the Physical Component Summary (PCS). The SF-12 consists of 12 items. Respondents are asked to rate quality of physical health, physical limitations, and to rate occurrence of emotional and physical difficulties. Sample questions include "During the past week how much of the time has your physical health and emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?" and "During the past week how much did pain interfere with your normal work (including both work outside the home and housework?)" (Ware et al., 1996, p. 225). Previous studies have shown that the MCS (.76 to.77) and PCS (.86 to .89) have acceptable test-retest reliability coefficients. The SF-12 was used in a previous study of the dynamic model of caregiver adjustment (Resch et al., 2012). It has been shown that the items on the SF-12 that best predicted the SF-36 were items deriving from certain subscales from physical health (Physical Functioning, Role Physical) and mental health (Role Emotional and Mental Health; Ware et al., 2006). Therefore, in the current study, the corresponding items for these subscales were tested for internal consistency. For the MCS, the subscale Mental Health showed an internal consistency of .74, and for Role Emotional an internal consistency of .86. For the Physical Component Summary, the subscale Physical Functioning revealed an internal consistency of .78, and for Role Physical an internal consistency of .91.

Procedure

Program directors of agencies associated with home community-based services programs were contacted to request authorization to collect data at their day habilitation

locations. Thirty-five out of 385 home community-based services providers that were listed on the Texas Department of Aging and Disability Services website had working telephone numbers, answered our calls, and had a day habilitation center. Four out of 35 HCBS agencies agreed to allow our researchers to collect data at their locations. Each program director provided us with an estimate of caregivers we may be able to recruit. For example, one agency estimated 150 caregivers, three different agencies estimated 50 caregivers at each site, and another (non-HCBS) reported 30 caregivers could be available. We expected to contact approximately 330 caregivers. In addition, we estimated a 50% response rate, which would give us an estimation of 145 total participants.

A total of 98 participants were enrolled; however, one dropped out of the study due to not having enough time to finish the survey. Researchers contacted 108 caregivers, and ten refused to participate in our study. A flyer was distributed a week prior to data collection at each agency inviting caretakers to participate in the study. One to three researchers were assigned per location with at least one graduate student from the research team at each location and at least one graduate researcher who was bilingual (Spanish-English speaking).

Participants were approached at the day habilitation centers as they entered and left the location. They were asked to participate in a face-to-face interview that took approximately 30-45 minutes to complete. Only two interviews lasted more than 1 hour, and this was due to participants' verbose conversational style. They were informed that in exchange of their participation they would be given the opportunity to enter a raffle to

win a $100 VISA gift card. Participants provided consent to participate in writing and verbally. When participants completed the face-to-face interview they were provided with verbal debriefing. In addition, they were provided with their raffle ticket. Tickets and consent forms were kept separately from surveys to ensure confidentiality. Participants were also provided with a referral list for mental health resources in their area.

CHAPTER IV

RESULTS

Descriptive Statistics of the Sample

Key demographic variables for investigation in this study included age of the

care recipient, relative status of the caregiver (i.e., was the caregiver a relative or a non-

relative), immigrant status (i.e., was the caregiver's birth country the United States or

another country), and gender. The majority of the caregivers reported that they provided

care for adults with ID ($n = 84$), 10 stated taking care of children with ID ($n = 10$), and

only 3 indicated taking care of both children and adults with ID.

A Pearson chi-square test found a statistically significant association between

gender and relative status, χ^2 (1, $n = 97$) = 28.19, $p < .0001$. Men who were non-relatives

were more likely to be caregivers ($n = 18$, 69.2%) than men who were relatives ($n = 8$,

30.8%). Women who were relatives were more likely to be caregivers ($n = 61$, 85.9%)

than women who were non-relatives ($n = 10$, 14.1%). A Pearson chi-square test found a

statistically significant association between gender and immigrant status, χ^2 (1, $n = 97$) =

29.51, $p < .0001$. Men whose birthplace was the United States were more likely to be

caregivers ($n = 23$, 88.5%) than those who were born in another country ($n = 3$, 11.5%).

Women who were born in another country were more likely to be caregivers ($n = 52$,

73.2%) than those who were born in the United States ($n = 19$, 26.8%). A Pearson chi-

square test found a statistically significant association between relative status and

immigrant status, χ^2 (1, $n = 97$) = 33.91, $p < .0001$. Relatives whose birthplace was not

the United States were more likely to be caregivers ($n = 52$, 75.4%) than relatives who were born in the United States ($n = 17$, 24.6%). Non-relatives who were born in the United States were more likely to be caregivers ($n = 25$, 89.3%) than those who were born in another country ($n = 3$, 10.7%).

PCS score differences were analyzed with a three-way ANOVA with relative status, immigrant status, and gender constituting the factors. There were no caregivers who were male, immigrant, and non-relatives. Because of this, the three-way interaction was not estimated. All means reported are estimated marginal means. Physical health composite scores (PCS) did not differ between relatives ($M = 42.26$, $SD = 1.91$) and non-relatives ($M = 49.27$, $SD = 3.53$), $F(1, 90) = 3.54$, $p = .06$. They also did not differ between U.S.-born ($M = 47.34$, $SD = 1.66$) and immigrant caregivers ($M = 44.18$, $SD = 4.24$), $F(1, 90) = .44$, $p = .51$. PCS scores also did not differ between men ($M = 44.21$, $SD = 3.49$) and women ($M = 47.32$, $SD = 1.82$), $F(1, 90) = .77$, $p = .38$. The two-way interaction between relative status and immigrant status was not statistically significant (U.S.-born, Relative: $M = 44.12$, $SD = 2.54$, U.S.-born, Non-relative: $M = 50.55$, $SD = 2.13$, Immigrant, Relative: $M = 40.37$, $SD = 2.84$, Immigrant, Non-relative: $M = 47.99$, $SD = 7.03$), $F(1, 90) = .03$, $p = .87$. The two-way interaction between gender and immigrant status was not statistically significant (Male, U.S.-born: $M = 44.94$, $SD = 2.41$, Male, Immigrant: $M = 43.47$, $SD = 7.03$, Female, U.S.-born: $M = 49.74$, $SD = 2.27$, Female, Immigrant: $M = 44.89$, $SD = 2.84$), $F(1, 90) = .20$, $p = .66$. Last, the two-way interaction between gender and relative status was not statistically significant (Male, Relative: $M = 38.44$, $SD = 3.49$, Male, Non-relative: $M = 49.97$, $SD = 5.52$, Female,

Relative: *M* = 46.07, *SD* = 1.54, Female, Non-relative: *M* = 48.56, *SD* = 3.29), *F*(1, 90) = 1.86, *p* = .18.

Differences on the Mental Health Composite scores (MCS) were similarly analyzed with a three-way ANOVA with relative status, immigrant status, and gender constituting the factors without the three-way interaction. All means reported are estimated marginal means. MCS scores did not differ between relatives (*M* = 53.94, *SD* = 2.42) and non-relatives (*M* = 47.97, *SD* = 4.50), *F*(1, 90) = 1.58, *p* = .21. They also did not differ between U.S.-born (*M* = 54.87, *SD* = 2.11) and immigrant caregivers (*M* = 47.05, *SD* = 5.39), *F*(1, 90) = 1.64, *p* = .20. MCS scores also did not differ between men (*M* = 52.06, *SD* = 4.44) and women (*M* = 49.86, *SD* = 2.31), *F*(1, 90) = .24, *p* = .63. The two-way interaction between relative status and immigrant status was not statistically significant (U.S.-born, Relative: *M* = 58.84, *SD* = 3.23, U.S.-born, Non-relative: *M* = 50.89, *SD* = 2.71, Immigrant, Relative: *M* = 49.04, *SD* = 3.61, Immigrant, Non-relative: *M* = 45.06, *SD* = 8.94), *F*(1, 90) = .18, *p* = .67. The two-way interaction between gender and immigrant status was not statistically significant (Male, U.S.-born: *M* = 57.47, *SD* = 3.07, Male, Immigrant: *M* = 46.65, *SD* = 8.94, Female, U.S.-born: *M* = 52.27, *SD* = 2.89, Female, Immigrant: *M* = 47.45, *SD* = 3.61), *F*(1, 90) = .38, *p* = .54. Last, the two-way interaction between gender and relative status was not statistically significant (Male, Relative: *M* = 54.00, *SD* = 4.44, Male, Non-relative: *M* = 50.12, *SD* = 7.02, Female, Relative: *M* = 53.88, *SD* = 1.96, Female, Non-relative: *M* = 45.83, *SD* = 4.19), *F*(1, 90) = .24, *p* = .62.

Path Model Estimation

        Model testing was completed using structural equation modeling (SEM). Data were analyzed using Mplus 7.4 (Muthen & Muthen, 2012) statistics software, which is typically used when conducting SEM analyses. Kline (2011) suggests a sample size of at least 100 as adequate for achieving a strong model fit. Our sample consisted of 97 participants. Model fit was tested using chi-square statistics and common fit indices, such as Comparative Fit Index (CFI), Tucker Lewis Index (TLI), Standardized Root Mean Square Residual (SRMR), and Root Mean Square Error of Approximation (RMSEA). Good model fit indices were specified by a CFI and TLI of at least .90, a RMSEA of $<.06$, a SRMR of $<.08$, and non-significant chi-square statistic (Weston, Gore, Chan, & Catalano, 2008). Additionally, parameter estimates were estimated using 5000 bootstrap samples. The bootstrapping method has been suggested in mediation models to better assess indirect effects with bias-corrected 95% confidence intervals (Hayes, 2009).

        Prior to conducting model estimation, we analyzed the data in three ways. First, we checked for missing values, and it was found that our data had no missing values within each of our variables. Second, in order to assess univariate normality, we computed skewness and kurtosis, and it was found that all variables in our data were normally distributed, and were within values of -3/+3 for skewness and kurtosis. While this does not provide definitive evidence, this is a good preliminary check for multivariate normality. Further, given the model also utilized bootstrapped standard errors, any deviation from multivariate normality would be generally accounted for.

Third, correlations between each of our variables were analyzed. It was found that each significant correlation between our variables correlated in the expected direction. These results are presented in Table 1.

A mediation path model was conducted to analyze the study's hypotheses. An a priori model was specified and included the RAS and RESS-Q variables as predictors, the Meaning in Caregiving, MLQ-Search, and MLQ-Presence variables as mediators, and the PCS and MCS composite scores as outcomes (see Figure 1.). Also estimated were the direct effects from predictors to outcomes, covariances between mediators, and residual covariances between outcomes. Given concerns regarding the limited sample size ($n = 97$) and adequately estimating all parameters, the analysis was conducted in two ways. The a priori model consisted of all variables as described above. The benefits of the a priori model included being able to model the covariance between mediators and obtain more accurate estimation of all model parameters. Each mediator was also included in its own model by itself to ensure that the model parameters were congruent with the a priori model, given the limited sample size. After conducting these three single-mediator path models, the results showed general congruence (similar size of coefficients and similar conclusions, e.g., p-values, indirect effect estimates) between the single mediator models and the a priori model. Thus, the a priori model is presented below.
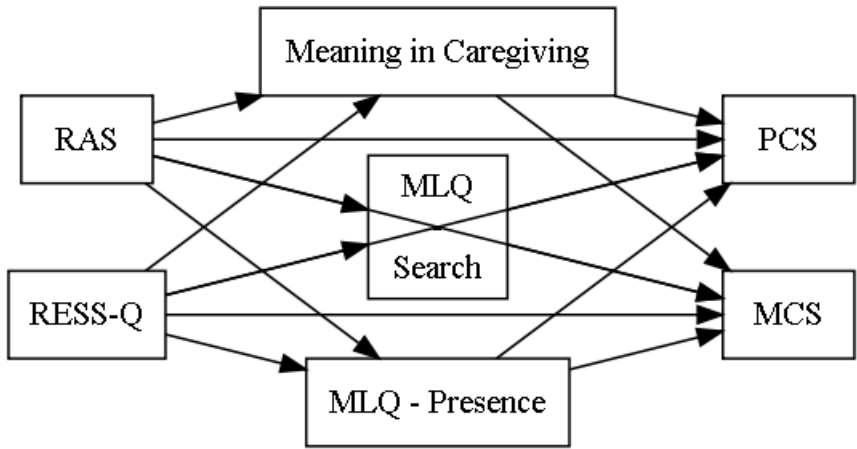
Figure 1
The a priori model for path analysis including all predictors, mediators, and outcomes.

Table 1
Descriptives and correlations of predictor, mediation, and outcome variables.

Measure	1	2	3	4	5	6	7
1. RAS	___						
2. RESSQ	-.05	___					
3. Meaning in Caregiving	-.35**	.08	___				
4. MLQ-Presence	-.21*	.01	.24*	___			
5. MLQ- Search	.08	-.90	-.05	-.12	___		
6. PCS	.11	.32**	-.19	-.05	.05	___	
7. MCS	-.16	.35**	.01	.13	-.38**	.08	___
N	97	97	97	97	97	97	97
M	12.90	44.98	37.90	31.23	17.76	45.57	52.07
SD	17.67	10.04	3.08	4.03	10.17	9.98	12.34
Range	0-63	19-63	29-40	20-35	5-35	15.49-60.15	13.76-68.69
Kurtosis	2.15	-.44	1.01	.35	-1.39	1.63	1.89
Skew	1.73	-.39	-1.47	-1.00	.15	-1.35	-1.48

Note. $p < .05^*, p < .01^{**}$

The a priori model was specified and estimated first to assess for multivariate outliers. Four participants (4%) were identified as multivariate outliers based on Cook's distance and Mahalanobis distance. These participants were removed from the model.

After the model was estimated, all paths were evaluated for statistical significance. All model parameters are presented in Table 2. There were five paths that were statistically significant: 1) RAS predicting MLQ – Presence ($ß = -.21$, $p < .05$), 2) RAS predicting Meaning in Caregiving ($ß = -.38$, $p < .0001$), 3) RESS-Q predicting PCS (direct effect; $ß = .45$, $p < .0001$), 4) RESS-Q predicting MCS (direct effect; $ß = .37$, $p < .0001$), and 5) MLQ – Search predicting MCS ($ß = -.29$, $p < .01$). All other paths in our a priori model were not statistically significant. Thirteen percent of the variance in Meaning in Caregiving ($R^2 = .13$) was explained or shared by the two predictors, RAS and RESS-Q. Four percent of the variance in MLQ – Presence ($R^2 = .04$) was explained or shared by the two predictors. A very small percentage of variance in MLQ – Search ($R^2 = .01$) was explained or shared by the two predictors. The two predictors and three mediators accounted for 16% of the variance of PCS ($R^2 = .16$), and 27% of the variance of MCS ($R^2 = .27$).

Table 2
Path model parameter estimates for the full model.

Dependent Variable	Independent Variable	Standardized Est.	S.E.	P-Value
	Maximum Likelihood Estimates From 5000 Bootstrap Samples			
MLQ – Presence				
	RAS	-0.21	0.02	$p < .05$
	RESS-Q	0.01	0.04	$p = .94$
MLQ – Search				
	RAS	0.05	0.05	$p = .56$
	RESS-Q	-0.09	0.11	$p = .42$
Meaning in Caregiving				
	RAS	-0.38	0.02	$p < .0001$
	RESS-Q	-0.02	0.03	$p = .82$
PCS				
	RAS	0.08	0.05	$p = .36$
	RESS-Q	0.45	0.08	$p < .0001$
	MLQ – Presence	0.01	0.23	$p = .96$
	MLQ – Search	0.03	0.09	$p = .78$
	Meaning in Caregiving	-0.14	0.29	$p = .13$
MCS				
	RAS	-0.10	0.05	$p = .20$
	RESS-Q	0.37	0.12	$p < .0001$
	MLQ – Presence	0.10	0.33	$p = .42$
	MLQ – Search	-0.29	0.11	$p < .01$
	Meaning in Caregiving	-0.01	0.35	$p = .89$
Meaning in Caregiving	With MLQ – Presence	0.19	1.21	$p = .09$
Meaning in Caregiving	With MLQ – Search	-0.07	2.62	$p = .48$
MLQ – Presence	With MLQ – Search	-0.12	3.87	$p = .24$
PCS	With MCS	-0.03	8.98	$p = .78$

Evaluation of Mediators and Indirect Effects

After running the a priori model and evaluating the paths that would be necessary for mediation, we decided to further explore and report the indirect effects of all three mediators even though not all paths needed for mediation were statistically significant.

Meaning in caregiving. We assessed whether meaning in caregiving would serve as a mediator between aggression toward caregivers (RAS) and caregiver well-being (PCS and MCS) and between resources and environmental/social characteristics (RESS-Q) and caregiver well-being (PCS and MCS). These mediation effects were assessed using bias-corrected 95% confidence intervals. Confidence intervals that included zero were indicative of non-significant indirect effects of predictors on outcomes through meaning in caregiving. Results found in Table 3 revealed that meaning in caregiving did not significantly mediate the relationship between our predictor and outcome variables in our model.

Table 3

Indirect effect estimates from predictor to outcome variables through meaning in caregiving in the full model.

Effect	Unstandardized Coefficient	Standardized Coefficient	Unstandardized 95% CI
RAS → Meaning in Caregiving → PCS	0.04	0.07	0.00 to 0.10
RAS → Meaning in Caregiving → MCS	0.02	0.03	-0.01 to 0.09
RESS-Q → Meaning in Caregiving → PCS	-0.01	-0.01	-0.07 to 0.02
RESS-Q → Meaning in Caregiving → MCS	-0.01	-0.01	-0.08 to 0.01

Note. Arrow indicates direct relation

Abbreviation: CI, bias-corrected bootstrap confidence interval estimated from 5000 bootstrap samples.

Presence of meaning in life. We also wanted to further examine if presence of meaning in life would mediate the relationship between aggression toward caregivers (RAS) and caregiver well-being (PCS and MCS) and between resources and environmental/social characteristics (RESS-Q) and caregiver well-being (PCS and MCS). Mediation effects were assessed using bias-corrected 95% confidence intervals. Confidence intervals that included zero were indicative of non-significant indirect effects of predictors on outcomes through presence of meaning in life. Results found in Table 4 showed that presence of meaning in life did not mediate the relationship between our predictor and outcome variables in our model.

Table 4

Indirect effect estimates from predictor to outcome variables through presence of meaning in life in the full model.

Effect	Unstandardized Coefficient	Standardized Coefficient	Unstandardized 95% CI
RAS → MLQ – Presence → PCS	-0.00	-0.00	-0.04 to 0.02
RAS → MLQ – Presence → MCS	-0.01	-0.02	-0.07 to 0.01
RESS-Q → MLQ – Presence → PCS	0.00	0.00	-0.02 to 0.02
RESS-Q → MLQ – Presence → MCS	0.00	0.00	-0.03 to 0.04

Note. Arrow indicates direct relation

Abbreviation: CI, bias-corrected bootstrap confidence interval estimated from 5000 bootstrap samples.

Search for meaning in life. We also wanted to further examine if search for meaning in life would mediate the relationship between aggression toward caregivers (RAS) and caregiver well-being (PCS and MCS) and between resources and environmental/social characteristics (RESS-Q) and caregiver well-being (PCS and MCS). These mediation effects were again assessed using bias-corrected 95% confidence intervals. Confidence intervals containing value of zero were indicative of non-significant indirect effects of predictors on outcomes through search for meaning. Results presented in Table 5 revealed that search for meaning in life did not mediate caregiver well-being in our model.

Table 5
Indirect effect estimates from predictor to outcome variables through search for meaning in life in the full model.

Effect	Unstandardized Coefficient	Standardized Coefficient	Unstandardized 95% CI
RAS → MLQ – Search → PCS	0.00	0.01	-0.01 to 0.03
RAS → MLQ – Search → MCS	-0.02	-0.03	-0.08 to 0.02
RESS-Q → MLQ – Search → PCS	-0.01	-0.01	-0.07 to 0.01
RESS-Q → MLQ – Search → MCS	0.03	0.03	-0.04 to 0.15

Note. Arrow indicates direct relation
Abbreviation: CI, bias-corrected bootstrap confidence interval estimated from 5000 bootstrap samples.

Model Re-specification

The a priori model was fully saturated using all available degrees of freedom. Consequently, it was not possible to adequately assess the fit of the model ($N = 93$; $\chi^2 = .00$; $p < .001$; RMSEA = .00; CFI = 1.00; TLI = 1.00; SRMR = .00). The model was re-specified by removing non-statistically significant paths (McCoach, 2003). The final model's chi-square value was less than its degrees of freedom leading to a good fit statistic ($N = 93$; $\chi^2 = 5.29$; $p = .63$; RMSEA = .00 (90% CI 0.00, 0.10); CFI = 1.00; TLI = 1.09; SRMR = .04). This re-specification was to better estimate the statistically significant predictors.

Parameter estimates did not change drastically after re-specifying: 1) direct path from resources and environmental/social characteristics (RESS-Q) to mental health composite score (MCS; $\beta = .33$, $p < .0001$), 2) direct path from resources and

environmental/social characteristics (RESS-Q) to physical health composite score (PCS;

($\beta = .33$, $p < .0001$), 3) direct path from search for meaning in life (MLQ – Search) to

mental health composite score (MCS; $\beta = -.34$, $p = .001$), 4) direct path from aggression

toward caregivers (RAS) to meaning in caregiving ($\beta = -.34$, $p = .001$), and 5) direct path

from aggression toward caregivers (RAS) to presence of meaning in life ($\beta = -.20$, $p =$

.07). It is important to note that the path from RAS to presence of meaning in life

became statistically insignificant after re-estimating. The re-specified model is presented
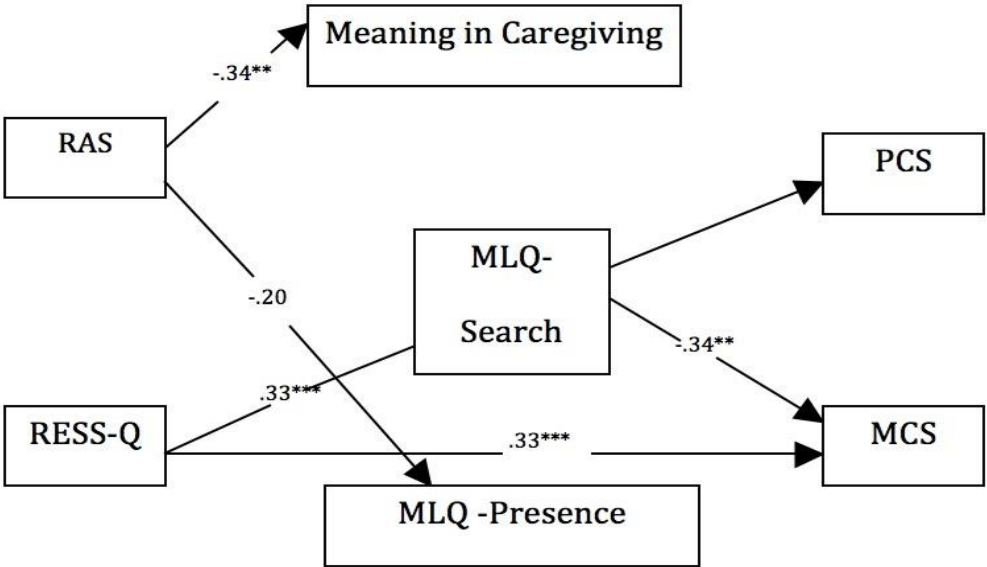
below.

Figure 2
The re-specified model for path analysis including all predictors, mediators, and
outcomes.

Post-Hoc Analyses

Post-hoc analyses were conducted to assess the possibility that presence of meaning in life moderated the relationship between search for meaning in life and caregiver well-being (mental health composite scores and physical health composite scores). First, we examined a possible interaction between search for meaning in life and presence of meaning in a regression equation to predict the mental health composite scores. In the first block, search for meaning in life (ß = -.37, *t* = -3.87, *p* < .001) significantly predicted mental health composite scores. Presence of meaning in life (ß = -.09, *t* = .92, *p* = .36) was not a significant predictor. In the second block, the Search for Meaning in Life X Presence of Meaning in Life interaction term was entered. The interaction term was not statistically significant (ß = -.46, *t* = -.61, *p* = .55). The results from this moderation analysis indicate that presence of meaning in life did not moderate the relationship between search for meaning in life and mental health composite scores.

Second, a similar interaction in the prediction of the physical health composite scores was examined. In the first block, search for meaning in life (ß = .04, *t* = .40, *p* = .69) and presence of meaning in life (ß = -.04, *t* = -.39, *p* = .70) did not predict physical health composite scores. In the second block, the Search for Meaning in Life X Presence of Meaning in Life interaction term was entered. The interaction term was not statistically significant (ß = -.65, *t* = -.79, *p* = .43). Results revealed that presence of meaning in life did not moderate the relationship between search for meaning in life and physical health composite scores.

Summary

These results indicate that resources and environmental/social characteristics (RESS-Q) contributed positively and significantly to caregiver mental and physical quality of life, as measured by the mental health (MCS) and physical health (PCS) subscales. The more caregivers felt positive supports in the environment, the greater their general well-being. Positive supports, as assessed by the RESS-Q, were significantly and directly predictive of physical and mental quality of life, independent of any perceived meaning caregivers may have reported. In addition, experiences of aggression from care-recipients had a significant and inverse effect on caregivers' sense of meaning in caregiving. Lastly, our data demonstrated that search for meaning in life contributed negatively to caregiver mental health. Paradoxically, higher levels of search for meaning in life among caregivers were significantly associated with lower levels of mental health. Research has found that individuals who search for meaning in life when they lack presence of meaning in life tend to have worse outcomes associated to their well-being (Steger et al., 2008). Therefore, we examined the moderation role of presence of meaning in life in search for meaning in life. Moderation analyses showed that presence of meaning in life did not moderate the relationship between search for meaning in life and caregiver well-being (mental health and physical health).

CHAPTER V

CONCLUSION

The aim of this study was to extend our understanding of the factors that influence caregiver adjustment. More specifically, we examined predictors associated with caregiver well-being and tested the role of perceptions of meaning in caregiving, presence of meaning, and search for meaning as mediators within the dynamic process model of caregiver wellbeing. Our results revealed a complex pattern inconsistent with our initial model, but rich with valuable information pertaining to caregiver well-being that add to the existing knowledge base. These results provide us with insights into the limits of social-cognitive processes in caregiver adjustment and the relative impact of positive supports in the caregiver environment that may potentially help policy makers, program developers, and clinicians who work with individuals with ID, their caregivers, and relatives.

In sum, our path analyses showed that meaning in caregiving, presence of meaning, and search for meaning did not mediate the relationship between our predictor variables (resources and environmental/social characteristics, aggression toward caregivers) and our outcome variables (mental health and physical health). Nevertheless, our data demonstrated that those caregivers who felt that their needs through positive supports were being met endorsed higher well-being (mental health and physical health-related quality of life). Caregivers who endorsed higher levels of search for meaning in life were more likely to report lower levels of mental health. When we assessed presence

of meaning in life as a moderator, it was shown that presence of meaning in life did not moderate the relationship between search for meaning in life and caregiver well-being (mental health and physical health). Lastly, caregivers who experienced aggression from care-recipients tended to endorse lower levels of meaning in caregiving and presence of meaning in life.

Positive Supports and Caregiver Adjustment

Across our two models we found that resources environmental/social characteristics positively contributed to caregiver well-being (mental and physical health-related quality of life). Our results echoed previous findings showing that resources and environmental supports play a significant role in caregiver well-being (Resch et al., 2012). They also provide additional support to models of caregiving, which suggest that social supports are a crucial component between the transactions that occur within the dynamic process of caregiving (e.g., Pearlin, Mullan, Semple, & Skaff, 1990). However, rather than using this variable as a predictor variable, future research should incorporate it as a mediator to further evaluate the mediating contributions of social supports. It is important to note that the majority of our caregivers participated in the home and community-based services (HCBS), which is a Medicaid waiver program in south Texas. HCBS resources are designed to support caregivers and care-recipients with residential services, such as foster care/host companion care, supportive home living, respite, specialized therapies, nursing, and dental services.

Through our qualitative reports from the resources and environmental/social characteristics measure caregivers were able to identify specific barriers and needs.

Caretakers reported "Service coordinators are not able to provide us with accurate information" and "Working with doctors is very challenging because they don't value caregiver opinions." Further, our data showed that immigrant caregivers face different challenges such as not being able to qualify for services due to their immigration status and language barriers. These caregivers reported the following "Even when he was a resident he was not able to get all the services," "Due to his legal status, we do not qualify for any services" and "Language is a barrier, my niece who speaks English helps me with the paperwork." Of note, caregivers who had barriers associated with immigration did not qualify to the HCBS program due to the care-recipient's immigration status and used private pay to receive day habilitation services. Our current qualitative data provide further understanding of how Latino caregivers face additional challenges and highly rely on family members for support, which supports previous findings discussed in this line of research (e.g., Cohen, 2013).

Research has shown that many individuals with ID continue to live with their families, yet only 13% of these families are given support at home (Braddock et al., 2013). Additionally, caregivers are typically faced with 10-year wait lists for Medicaid waiver services (Hewitt, Agosta, Heller, Williams, & Reinke, 2013); one of our participants stated the following "I fought and struggled to get the services, but at the end it was worth it, I hope I never lose services". Another major issue is that caregivers are confronted with barriers such as lack of awareness and knowledge about these programs (Hewitt et al., 2013). Caregivers explained the following, "I do not know where to go for services. There is no information out there on what services he qualifies

for. Don't know where to start" and "We typically find out about services through other parents; we cannot rely on professionals to help us acquire services or information". Overall, our study demonstrated that there are many barriers perceived by caregivers, especially if they immigrated to the United States, and these barriers are negatively contributing to overall mental and physical health. Therefore, more efforts need to be made by lawmakers to make supports and services accessible to this population.

Nevertheless, the extant body of research on caregiver needs and resources has led to innovative ways of supporting caregivers and their families. More recently, scholars and practitioners are moving towards a more holistic way of providing services to care recipients by treating the care-recipient as a "unit" rather than an "individual" (e.g., Heller, Caldwell, & Factor, 2007; Hewitt et al., 2013; Holl & Morano, 2014). Programs that have focused on supporting family members have shown positive outcomes such as reduced stress, financial worries, and out-of-home placements, and an increase in self-efficacy, satisfaction with services, and maternal employments (e.g., Heller et al., 2007; Hewitt et al., 2013; Holl & Morano, 2014). Further, new service delivery models are emerging allowing caregivers to hire family members and friends. These programs have resulted in facilitating selection and retention of staff as well as assessing the family needs rather than solely the care recipient's needs (e.g., Bogenschutz, Hewitt, Hall-Lande, & Laliberte, 2010). These advancements are important since care-recipients at times outlive their primary caregivers (e.g., parents), and family members such as siblings are beginning to take caregiving responsibilities (Hewitt et al., 2013; Holl & Morano, 2014).

Technology and peer support groups can also be used as outlets for caregivers. Peer support can help caregivers make important decisions regarding legal matters (e.g., guardianship) as well as future planning and finances (Heller & Caldwell, 2006). Further, Perkins and LaMartin (2012) found that online support groups can increase caregiver well-being and life satisfaction. These are particularly convenient to caregivers who may not have adequate transportation and time constraints due to caregiving tasks. However, these groups have also shown to have some challenges such as obtaining misinformation and excluding caregivers that do not have access to a computer and/or the Internet, have low literacy, and may find it culturally inappropriate to find support via the Internet (Perkins & LaMartin, 2012). One of our participants explained the following, "I would like to learn more English and how to use the computer but there are not many services available here".

Shortage of federal and state funding along with limited culturally-sensitive programs have resulted in inadequate service delivery programs and major challenges for caretakers. Nonetheless, through advocacy and research advancements changes to policy and programming have been possible. Presently, we have a more humane and holistic way of viewing individuals with ID and their families. Through our qualitative reports caregivers were able to express appreciation and positive attitudes when they felt their needs were being met: "I have always been happy with the services. We are blessed with good people helping us".

The Limits of Appraisal Activities in the Caregiving Experience

The dynamic model of caregiving, similar to the initial model of adjustment to disability from which it was derived (Elliott, Kurylo, & Rivera, 2002), places a high premium on the influence of subjective appraisal activity on self-reported adjustment. Results of the present study found no evidence that meaning (presence of meaning in life, search for meaning, and meaning in caregiving) had any mediating effects on the relationships between experiences of care-recipient aggression or positive supports with the indicators of mental and physical health-related quality of life. This finding contradicts theoretical frameworks (e.g., Pearlin et al., 1990), which posit that coping mechanisms serve as mediating factors by strengthening the relationship between transactions within contextual models of caregiving. More research is required to further understand how meaning in general is associated with coping mechanisms among caregivers of individuals with ID. Nevertheless, we were able to demonstrate that meaning plays an important role in the caregiving experience.

For instance, our study found that caregivers who experienced aggression from care recipients were more likely to report lower levels of meaning in caregiving. Our findings support studies that have found that caregivers who experience aggression by care-recipients report a longing for meaning (e.g., Hellzen & Asplund, 2002). Research suggests that care-recipient problem behaviors have a negative effect on caregiver social-cognitive activity, which is theoretically influential in their personal adjustment (e.g., attributions for care-recipient behavior; Hui, Elliott, Martin, & Uswatte, 2011). Consistent with this previous study, the current results imply that care-recipient problem

behaviors, and perhaps care-recipient aggression toward caregivers, specifically may override the potential benefits of subjective, social-cognitive appraisal activities, which could otherwise be considered potentially beneficial to caregiver adjustment. For instance, Erosa and colleagues (2010) found that those caregivers who did not experience aggression reported higher levels of life satisfaction compared to those who reported incidents of aggression. Our findings also provide further evidence of the coping-stress model proposed by Pearlin and colleagues (1990) who describe care-recipient self-harm and aggression toward others as a primary stressor within the caregiving experience and emphasizes the importance of the caretaker-care-recipient relationship.

Through informal reports during the interview process we observed resistance and minimization when reporting experienced aggression. For instance, participants made statements such as, "Yes, he will spit or kick, but we are used to it. That's how he is. It's part of his condition" and "It only happened one time; he does not do that anymore". Studies have demonstrated that aggression toward caregivers is underreported and for that reason it can be challenging to study (Cahill & Shapiro, 1993; Menckel et al., 2000; Strand et al., 2004). One plausible explanation for underreporting can be that family violence is a taboo among caregivers, or caregivers have learned to habituate to the care recipient's aggressive behavior (Lundstrom, Astrom, & Graneheim, 2007; Sandvide, Astrom, Norberg, & Saveman, 2004). Nonetheless, research has found that approximately 61% of caregivers experienced aggression from adults with intellectual disabilities (Strand et al., 2004). In order to debunk myths and minimize taboos

associated with aggression toward caregivers, psychoeducation programs need to be developed so that caregivers are able to accurately report these incidents of violence, seek formal social support, effectively implement behavioral plans, problem solve, and openly discuss their experiences. It seems imperative for mental health professionals to have a better understanding of the factors that hinder a sense of personal meaning among caregivers. Our results suggest that aggression experienced by caregivers from care recipients might potentially encumber the psychological process of making meaning in caregiving and meaning in life.

Meaning is a multifaceted and complex psychological process that requires further scrutiny from scholars. This will allow for the development of innovative psychological treatments based on existential constructs that can aid mental health professionals who work with caregivers of individuals with intellectual disabilities and their families. For instance, although meaning tends to be a concept that is difficult to address scientifically due to its humanistic, philosophical, and spiritual nature (Noonan & Tennstedt, 1997; Park & Peterson, 2009), those who have made efforts to advance this area of research have found that it can successfully be used as a theoretical framework in psychological interventions (e.g., Noonan et al., 1997; Reker et al., 1987). Frankl's logotherapy, Morita psychotherapy, structured written emotional expression (SWEE), and reminiscence has been utilized to increase meaning life and well-being. (Butcher & Buckwalter, 2002; Reynolds, 1976; Wong, 1997). SWEE in particular has shown to have positive health benefits, reduce stress, increase positive affect, and increase immune function (Butcher & Buckwalter, 2002).

Search for meaning in life and presence of meaning in life have been treated as two different constructs in the meaning literature (Steger et al., 2006). As discussed earlier, research suggests that individuals who already have a sense of meaning in life and engage in search for meaning tend to score high on constructs related to well-being (e.g., Steger et al., 2006; Park, Park, & Peterson, 2010). Conversely, those who lack meaning in life and are on a continuous journey to search for meaning in life tend to report lower quality of life (e.g., Steger et al., 2006; Park et al., 2010). In our current study, meaning in caregiving was negatively impacted by caregiver-experienced aggression from care-recipient, and search for meaning contributed negatively to mental health scores. Although we suspected that this relationship might be due to the moderation role of presence of meaning in life, this resulted to not be the case. Post-hoc analyses found that presence of meaning in life did not moderate the relationship between search for meaning in life and caregiver well-being (mental health and physical health). It is possible that caregivers were searching for meaning in their caregiving situation, which resulted in lower mental health well-being. There is some evidence that when individuals make attempts to find meaning in adversity this can negatively impact their well-being (Steger, Oishi, & Kesebir, 2011).

Another potential factor for these results may be ethno-cultural differences. Research has found that search for meaning and happiness tends to be different across cultures (Steger, Kawabata, Shimai, & Otake, 2008). Caregivers of color have shown to appraise their caregiver experiences differently compared to White caregivers (e.g., Janevic & Connell, 2001; Wallhagen & Yamamoto-Mitani, 2006). For instance,

Japanese caregivers have shown to have a strong sense of fulfillment, pride, and self-worth out of caregiving (Yamamoto & Wallhagen, 1997), while American caregivers perceived caregiving as an "unexpected career", and caregiving tasks having a negative long-term impact in their lives (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Wallhagen and Yamamoto-Mitani (2006) explain that most research examining caregiver experiences and interventions have relied on samples from Western countries. Therefore, scholars and practitioners should consider multicultural factors associated with the way caregivers appraise their caregiving situation such as making meaning in caregiving.

During our interviews participants who were Mexican immigrants responded in a positive manner when asked about meaning in caregiving. Some responses included, "Of course I enjoy the time I spend with my son" and "I am happy to take care of my daughter. I wouldn't have it any other way" and "I am always learning from my son". To our knowledge little is known about how Mexican immigrant caregivers of individuals with ID process meaning in caregiving within their caregiver appraisals. For instance, John and colleagues (1997) suggest that familism may play an important role in the way Latino caregivers appraise their caregiving situation. It is important to note that Mexican immigrant caregivers may not be reporting accurate levels of meaning in caregiving and depression in their attempt to appear in a positive manner since positive appraisals in regards to family caregiving may potentially be a prescribed cultural norm. Neary and Mahoney (2005) found that Latino caregivers of relatives who suffered from dementia experienced tension between cultural beliefs and the demands of their individual

circumstances. Furthermore, Losada and colleagues (2010) suggest that attitudinal

familism within Latinos is based on the notion that caregivers are required to care for a

lovee one; however, this type of belief was shown to increase caregiver distress. It is

possible, that caregivers who appraise their caregiving experience in this manner may be

feeling captive in their caregiver role (Pearlin et al., 1990).

Issues Concerning Caregiver Demographic Information

We did not find statistical differences when we examined demographic variables

among caregivers. However, female caregivers and immigrant caregivers tended to

report lower levels of well-being. More specifically, female caretakers reported lower

mental health composite scores, whereas immigrant caretakers indicated lower mental

health and physical health composite scores. Furthermore, female caregivers and

immigrant caregivers were more likely to be relatives of care-recipients compared to

male caregivers and U.S born caregivers. Not surprising, previous findings have

demonstrated that female caregivers tend to experience higher levels of burden, and

immigrant caregivers tend to engage in more time-intensive caregiving or self-

sacrificing roles: "marianismo" (e.g., Chappell, Dujela, & Smith, 2015; Mendez-Luck &

Anthony, 2016; Rote & Moon, 2016). Studies have found that family supports play a

major role in decreasing caretaker stress and improving self-efficacy among Latino

mothers of children with ID (e.g., Correa, Bonilla, & Reyes-MacPherson, 2010; Magana,

Schwartz, Rubert, Szapocznik, & Floyd, 2006). Therefore, scholars have suggested that

research efforts are needed to improve our understanding on how to adapt support

systems to be more family centered and culturally relevant to Latino caregivers (e.g.,

Cohen, 2013). Demographic caregiver characteristics are vital when examining caregiving well-being since immigrant caregivers and female caregivers may be at a higher risk of caregiver burden.

Limitations and Strengths

Several limitations and strengths to our study are important to discuss. First, the majority of our participants were part of the HCBS program. Although during informed consent participants were explained that our research was not affiliated with the HCBS program, it could be possible that participants continued to feel wary about their responses and feared interruption of services. Also, it did not allow us to fully assess barriers and challenges experienced by those caregivers who did not receive services from a formal support system. Secondly, our research was a self-reported method using interviews, which limited anonymity of responses. In particular, responses related to aggression towards caregivers, mental health, and meaning in caregiving could have been impacted by social desirability. Perhaps caregivers did not want to be perceived as unsuitable to care for the care recipient. Third, external validity was another limitation of our study. Only four HCBS providers agreed to allow us to collect data at their day habilitation programs. Consequently, we were not able to obtain a large sample, and our findings can only be applicable to a small percentage of caregivers of individuals with ID who reside in South Texas. Further, although we were able to collect data from Latino caretakers, within group variability continues to be a problem when conducting research with populations of color (Paniagua & Yamada, 2013). Last, due to time

constraints we did not use the full meaning in caregiving scale, which could have provided insight on the role of religion and spirituality in caregiving.

Despite these few limitations, this study had several strengths. First, we collected data from Mexican immigrant caregivers of individual with ID, which is generally considered to be a hard to reach and invisible population. Second, our self-reported method using interviews allowed for our study to be inclusive. For instance, individuals with low levels of education who did not know how to read and write and had never used a computer were able to participate. Additionally, this method facilitated rapport and permitted researchers to probe when required. Third, our interviews were conducted in both English and Spanish with community samples. Fourth, this mixed method study using quantitative and a qualitative primary data collection allowed us to collect additional data on caregivers' experiences related to resources and barriers. Lastly, to our knowledge we are the first to simultaneously examine meaning and aggression towards caregivers within a contextual model of caregiver well-being.

Future Direction

The present study provides us with insight into factors described in the dynamic process of caregiver well-being that have considerable influence on health-related quality of life reported by caregivers of persons with ID. Similar to our findings, others have found that a variety of factors contribute to caregiver burden, in particular, a lack of resources and support systems (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Efforts are needed at all levels to develop the best possible strategies to decrease caregiver burden and increase access to resources. Our findings showed that even among

caregivers who are already receiving an array of resources, environmental/social characteristics remain an important factor in caregiver well-being. Scholars should continue their efforts to expand this line of research to better aid policy makers and program developers' work related to caregiving. For instance, quality assurance measures can potentially ensure that resources are being implemented according to the multifaceted and dynamic experiences of caregivers.

Lastly, forthcoming research examining Latino caregivers should examine within group differences by utilizing a measure that accounts for this variability. For instance, measures targeting familism, acculturation, and acculturative stress could provide us with more information about the psychological process of Latino caregivers residing in the United States. More efforts need to be made to develop measures that are culturally appropriate. For instance, during our interviews Mexican immigrant participants who were older had the most difficulty responding to Likert scales, and tended to provide dichotomous answers, such as "yes" or "no," and "0" or "10". Qualitative measures and pilot studies can further aid scholars develop adequate measures when working with diverse populations of caregivers. Further, extensive work on the various dimensions of making meaning is needed in order to have a better understanding of its process and should include measures of spirituality and religiosity within contextual models of caregiving. Scholars should also focus on the reciprocal process of aggression within the caregiving relationship. More information and training on aggression could potentially decrease taboos and stigma associated with family violence.

Summary

After testing the hypothesized model, it was found that social and environmental characteristics contributed positively to caregiver well-being (mental health and physical health), aggression toward caregivers negatively contributed to meaning in caregiving, and search for meaning in life contributed negatively to caregiver mental health. Additionally, meaning (presence, search, meaning in life) did not mediate the relationship between our predictor variables (social and environmental characteristics, aggression toward caregivers) and caregiver well-being (mental health and physical health). A plausible explanation is that what was identified as an appraisal process in our model (meaning) could have been behaving as an outcome variable. For instance, in the past scholars have used meaning in life as an indicator of well-being (e.g., Ivtzan, Chan, Gardner, & Prashar, 2013), and others have found that meaning is related to an array of well-being constructs (Steger, 2017).

Since our sample was predominately Mexican immigrant, perhaps other variables could have been explored within the hypothesized model. For instance, marianismo (e.g., self-sacrificing attitudes) and familism (e.g., duty to care for family members) could potentially serve as constructs that identify culturally-defined family values and mediate or moderate transactions occurring within contextual models of caregiver well-being. It was also found that search for meaning in life was not moderated by presence of meaning in life, which indicates that there are other factors contributing to the negative relationship between search for meaning in life and caregiver mental health. Possibly caregivers were attempting to make meaning of their caregiving situation while

experiencing caregiver burden, which has shown to be detrimental to well-being (e.g., Steger, Oishi, & Kesebir, 2011). Researchers should further examine appraisals about family and caregiving roles and how these interact within the dynamic process model of caregiver well-being. This would provide us with a culture-specific model and more insight into the ethno-multicultural caregiving experience.

Our results provided us with valuable information on factors that may be contributing to caregiver coping mechanisms such as meaning in caregiving, search for meaning, experienced aggression from care recipients, and positive supports. Moreover, the current study allowed for an open discussion on the fundamental role of ethno-multicultural factors within the dynamic process of caregiving. It would be a disservice to caregivers to underestimate the complexity of their caregiving experience; therefore, continuous research efforts are needed to examine caregiver well-being in a holistic manner to better inform law makers and program developers.

REFERENCES

Adelman, R. D., Tmanova, L. L., Delgado, D., Dion, S., & Lachs, M. S. (2014). Caregiver burden: A clinical review. *Journal of American Medical Association*, *311*(10), 1052-1060.

Affleck, G., Allen, D. A., Tennen, H., McGrade, B. J., & Ratzan, S. (1985). Causal and control cognitions in parent's coping with chronically ill children. *Journal of Social and Clinical Psychology*, *3*(3), 367-377.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego, CA: Academic Press.

Antonovsky, A. (1979). *Health, stress, and coping.* San Francisco, CA: The Jossey-Bass Social and Behavioral Science Series.

Archbold, P. G. (1983). Impact of parent-caring on women. *Family Relations*, *32*(1), 39-45.

Arno, P. S., Levine, C., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs, 18*(2), 182-188.

Baker, B. L., Blacher, J., Kopp, C. B., & Kraemer, B. (1997). Parenting children with mental retardation. *International Review of Research in Mental Retardation*, *20*(1), 1-45.

Battista, J., & Almond, R. (1973). The development of meaning in life. *Psychiatry*, *36*(4), 409-427.

Beckman, P. J. (2002). Providing family-centered services. In M. Batshaw (Ed.),

    Children with disabilities : *A medical primer* (pp. 683–691). Baltimore, MD:

    Brookes.

Ben-Zur, H., Duvdevany, I., & Lury, L. (2005). Associations of social support and

    hardiness with mental health among mothers of adult children with intellectual

    disability. *Journal of Intellectual Disability Research*, *49*(1), 54-62.

Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture.

    American Journal of Mental Retardation, 106(2), 173-188.

Blackburn, C., & Read, J. (2005). Using the Internet? The experiences of parents of

    disabled children. *Child: Care, Health and Development*, *31*(5), 507-515.

Bogenschutz, M., Hewitt, A., Hall-Lande, J., & LaLiberte, T. (2010). Status and trends

    in the direct support workforce in consumer directed supports. *Intellectual and

    Developmental Disabilities, 48*(5), 345-360.

Bouma, R., & Schmeitzer, R. (1990). The impact of chronic childhood illness on family

    stress: A comparison between autism and cystic fibrosis. *Journal of Clinical

    Psychology*, *46*(6), 722–730.

Braddock, D., Emerson, E., Felce, D., & Stancliffe, R. J. (2001). Living circumstances

    of children and adults with mental retardation or developmental disabilities in the

    United States, Canada, England and Wales, and Australia. *Mental Retardation

    and Developmental Disabilities Research Reviews*, *7*(2), 115-121.

Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., Lulinski, A., & Wu, J.

    (2013). *The state of the states in developmental disabilities 2013: The great*

recession and its aftermath (Prelim. ed.). Boulder, CO: Department of Psychiatry

and Coleman Institute, University of Colorado, and Department of Disability and

Human Development, University of Illinois at Chicago, Boulder.

Butcher, H. K., & Buckwalter, K. C. (2002). Exasperations as blessings: Meaning-

making and the caregiving experience. *Journal of Aging and Identity*, *7*(2), 113-

132.

Cahill, S., & Shapiro, M. (1993). 'I think he might have hit me once': Aggression

towards caregivers in dementia care. *Australian Journal on Ageing*, *12*(4), 10-15.

Caldwell, J. (2008). Health and access to health care of female family caregivers of

adults with developmental disabilities. *Journal of Disability Policy Studies*,

19(2), 68-79.

Chappell, N. L., Dujela, C., & Smith, A. (2015). Caregiver well-being: intersections of

relationship and gender. *Research on Aging*, *37*(6), 623-645.

Cheseldine, S. E., & Jeffree, D. M. (1981). Mentally handicapped adolescents: Their use

of leisure. *Journal of Intellectual Disability Research*, *25*(1), 49-59.

Chen, Y. L., Ryden, M. B., Feldt, K., & Savik, K. (2000). The relationship between

social interaction and characteristics of aggressive, cognitively impaired nursing

home residents. *American Journal of Alzheimer's Disease and Other

Dementias*, *15*(1), 10-17.

Cohen, S. R. (2013). Advocacy for the "Abandonados": Harnessing cultural beliefs for

Latino families and their children with intellectual disabilities. *Journal of Policy

and Practice in Intellectual Disabilities*, *10*(1), 71-78.

Cooney, C., & Howard, R. (1995). Abuse of patients with dementia by carers—out of

sight but not out of mind. *International Journal of Geriatric Psychiatry*, *10*(9),

735-741.

Cooper, S. A., Smiley, E., Jackson, A., Finlayson, J., Allan, L., Mantry, D., & Morrison,

J. (2009). Adults with intellectual disabilities: Prevalence, incidence and

remission of aggressive behaviour and related factors. *Journal of Intellectual*

Disability Research, *53*(3), 217-232.

Correa, V. I.*,* Bonilla, Z. E.*, &* Reyes-MacPherson, M. E. *(*2010*).* Support networks of

single Puerto Rican mothers of children with disabilities. *Journal of Child and*

Family Studies, *20*(1), 66–77.

Crocker, A. G., Mercier, C., Lachapelle, Y., Brunet, A., Morin, D., & Roy, M. E. (2006).

Prevalence and types of aggressive behaviour among adults with intellectual

disabilities. *Journal of Intellectual Disability Research*, *50*(9), 652-661.

Crumbaugh, J. C., & Maholick, L. T. (1964). An experimental study in existentialism:

The psychometric approach to Frankl's concept of noogenic neurosis. *Journal of*

Clinical Psychology, *20*(2), 200-207.

Cummins, R., A. (2001). The subjective well-being of people caring for a family

member with severe disability at home: A review. *Journal of Intellectual and*

Developmental Disability, 26(1), 83-100.

Davis, K., & Gavidia-Payne, S. (2009). The impact of child, family, and professional

support characteristics on the quality of life in families of young children with

disabilities. *Journal of Intellectual and Developmental Disability*, *34*(2), 153-162.

Diener, E., & Chan, M. Y. (2011). Happy people live longer: Subjective Well-being contributes to health and longevity. *Applied Psychology: Health and Well-Being*, *3*(1), 1-43.

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research A 20-year review (1980–2000). *The Gerontologist*, *42*(2), 237-272.

Donenberg, G., & Baker, B. L. (1993). The impact of young children with externalizing Behaviors on their families. *Journal of Abnormal Child Psychology, 21*(2), 179-198.

Eisenhower, A., & Blacher, J. (2006). Mothers of young adults with intellectual disability: Multiple roles, ethnicity and well-being. *Journal of Intellectual Disability Research*, *50*(12), 905-916.

Elliott, T. R., Kurylo, M., & Rivera, P. (2002). Positive growth following an acquired physical disability. In C. R. Snyder & S. Lopez (Eds.), *Handbook of positive psychology* (pp. 687-699). New York, NY: Oxford University Press.

Elliott, T. R., & Mullins, L. L. (2004). Counseling families and children with disabilities. In D. Atkinson & G. Hackett (Eds.), *Counseling d*i*verse populations* (3rd Ed.; pp. 151–170). New York, NY: McGraw-Hill.

Elliott, T. R., & Parker, M. (2012). Family caregivers and health care providers: Developing partnerships for a continuum of care and support. In R. C. Talley &

J. E. Crews (Eds.), *Multiple dimensions of caregiving and disability* (pp. 135-152). New York, NY: Springer.

Elliott, T. R., Patnaik, A., Naiser, E., Fournier, C. J., McMaughan, D. K., Dyer, J. A., & Phillips, C. D. (2014). Medicaid personal care services for children with intellectual disabilities: What assistance is provided? When is assistance provided? *Mental Retardation*, *52*(1), 24-31.

Erosa. N. A., Elliott, T. R., Berry, J. W., & Grant, J. S. (2010). Verbal and physical abuse experienced by family caregivers of adults with severe disabilities. *Italian Journal of Public Health, 8*(7), 76-84.

Farran, C. J. (1997). Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: Stress/adaptation and existentialism. *The Gerontologist*, *37*(2), 250-257.

Farran, C. J., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, S. C. (1991). Finding meaning: An alternate paradigm for Alzheimer's disease family caregivers. *The Gerontologist, 31*(4), 483-489.

Farran, C. J., Miller, B. H., Kaufman, J. E., Donner, E., & Fogg, L. (1999). Finding meaning through caregiving: Development of an instrument for family caregivers of persons with Alzheimer's disease. *Journal of Clinical Psychology*, *55*(9), 1107-1125.

Ferguson, P. M., Ferguson, D. L., & Jones, D. (1988). Generations of hope: parental Perspectives on the transition of their children with severe mental retardation from school to adult life. *Journal of the Association for Persons with Severe*

Handicaps, 13(3)*,* 177-187.

Frankl, V. E. (1985). *Man's search for meaning*. Boston, MA: Simon and Schuster.

Frankl, V. E. (2005). *On the theory and therapy of mental disorders: An introduction to logotherapy and existential analysis*. New York, NY: Brunner-Routledge.

Frankl, V. E. (2014). *The will to meaning: Foundations and applications of logotherapy*. New York, NY: Plume.

Franz, S., Zeh, A., Schablon, A., Kuhnert, S., & Nienhaus, A. (2010). Aggression and violence against health care workers in Germany—A cross sectional retrospective survey. *BMC Health Services Research*, *10*(1), 51.

Freedman, R. I., & Boyer, N. C. (2000). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health & Social Work*, *25*(1), 59-68.

Ganellen, R. J., & Blaney, P. H. (1984). Hardiness and social support as moderators of the effects of life stress. *Journal of Personality and Social Psychology*, *47*(1), 156.

Gates, D. M., Fitzwater, E., & Meyer, U. (1999). Violence against caregivers in nursing homes. Expected, tolerated, and accepted. *Journal of Gerontological Nursing*, *25*(4), 12-22.

Gates, D., Fitzwater, E., & Succop, P. (2005). Reducing assaults against nursing home caregivers. *Nursing Research*, *54*(2), 119-127.

George, L. K., & Gwyther, L. P. (1986). Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *The Gerontologist*, *26*(3), 253-259.

Grant, G., & McGrath, M. (1990). Need for respite-care services for caregivers of persons with mental retardation. *American Journal on Mental Retardation*, *94*(6), 638-648.

Green, S. E. (2007). "We're tired, not sad": Benefits and burdens of mothering a child with a disability. *Social Science & Medicine*, *64*(1), 150-163.

Gunn, P., & Berry, P. (1987). Some financial costs of caring for children with down Syndrome at home. *Australian and New Zealand Journal of Developmental Disabilities, 13*(4), 187-193.

Guttmann, D. (1996). *Logotherapy for the helping professional: Meaningful social work*. New York, NY: Springer Publishing Co.

Haley, W. E., & Perkins, E. A. (2004). Current status and future directions in family caregiving and aging people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 1*(1), 24-30.

Hamel, M., Gold, D. P., Andres, D., Reis, M., Dastoor, D., Grauer, H., & Bergman, H. (1990). Predictors and consequences of aggressive behavior by community-based dementia patients. *The Gerontologist*, *30*(2), 206-211.

Harlow, L. L., Newcomb, M. D., & Bentler, P. M. (1986). Depression, self-derogation, substance use, and suicide ideation: Lack of purpose in life as a mediational factor. *Journal of Clinical Psychology*, *42*(1), 5-21.

Hastings, R. P., Allen, R., McDermott, K., & Still, D. (2002). Factors related to positive

    perceptions in mothers of children with intellectual disabilities. *Journal of*

    Applied Research in Intellectual Disabilities, *15*(3), 269-275.

Hastings, R. P., & Taunt, H. M. (2002). Positive perceptions in families of children with

    developmental disabilities. American *Journal of Mental Retardation*, *107*(2),

    116-27.

Hayden, M. F., & Goldman, J. (1996). Families of adults with mental retardation: stress

    levels and need for services. *Social Work*, *41*(6), 657-667.

Hayden, M. E., & Heller, T. (1997). Support, problem-solving/coping ability, and

    personal burden of younger and older caregivers of adults with mental

    retardation. *Mental Retardation*, *35*(5), 364-372.

Haveman, M., Van Berkum, G., Reijnders, R., & Heller, T. (1997). Differences in

    service needs, time demands, and caregiving burden among parents of persons

    with mental retardation across the life cycle. *Family Relations, 46*(4), 417-425.

Hayes, A. F. (2009). Beyond Baron and Kenny: Statistical mediation analysis

    in the new millennium. *Communication Monographs, 76*(4), 408-420.

Helff, C. M., & Glidden, L. M. (1998). More positive or less negative? Trends in

    research on adjustment of families rearing children with developmental

    disabilities. *Mental Retardation*, *36*(6), 457-464.

Heller, T., & Caldwell, J. (2006). Supporting aging caregivers and adults with

    developmental disabilities in future planning. *Mental Retardation*, *44*(3), 189-

    202.

Heller, T., Caldwell, J., & Factor, A. (2007). Aging family caregivers: Policies and

practices. *Mental Retardation and Developmental Disabilities Research Reviews*,

13(2), 136-142.

Heller, T., Hsieh, K., & Rowitz, L. (2000). Grandparents as supports to mothers of

persons with intellectual disability. *Journal of Gerontological Social Work*,

33(4), 23-34.

Heller, T., Miller, A. B., & Factor, A. (1997). Adults with mental retardation as supports

to their parents: Effects on parental caregiving appraisal. *Mental Retardation*,

35(5), 338-346.

Hellzen O., & Asplund, K. (2002) Being in fragmented and isolated world: Interviews

with carers working with a person with severe autistic disorder. *Journal of

Advanced Nursing, 37*(4), 346-354.

Hensel, J. M., Lunsky, Y., & Dewa, C. S. (2012). Exposure to client aggression and

burnout among community staff who support adults with intellectual disabilities

in Ontario, Canada. *Journal of Intellectual Disability Research*, *56*(9), 910-915.

Hewitt, A., Agosta, J., Heller, T., Williams, A. C., & Reinke, J. (2013). Families of

individuals with intellectual and developmental disabilities: Policy, funding,

services, and experiences. *Intellectual and Developmental Disabilities*, *51*(5),

349-359.

Ho, M. Y., Cheung, F. M., & Cheung, S. F. (2010). The role of meaning in life and

optimism in promoting well-being. *Personality and Individual Differences*,

48(5), 658-663.

Hocking, M. C., & Lochman, J. E. (2005). Applying the transactional stress and coping

    model to sickle cell disorder and insulin-dependent diabetes mellitus: Identifying

    psychosocial variables related to adjustment and intervention. *Clinical Child and*

    Family Psychology Review, *8*(3), 221-246.

Holden, B., & Gitlesen, J. P. (2003). Prevalence of psychiatric symptoms in adults with

    mental retardation and challenging behaviour. *Research in Developmental*

    Disabilities, *24*(5), 323-332.

Holl, E., & Morano, C. L. (2014). Supporting the next generation of caregivers: service

    use and needs of adult siblings of individuals with intellectual disability.

    American Association on Intellectual and Developmental Disabilities, 2(1), 2-16.

Hui, S. K. A., Elliott, T. R., Martin, R., & Uswatte, G. (2011). Family caregiver

    attributions about care-recipient behavior: Does relationship satisfaction mediate

    the attribution-distress relationship? *British Journal of Health Psychology, 16*(3),

    642-659.

Ivtzan, I., Chan, C. P., Gardner, H. E., & Prashar, K. (2013). Linking religion and

    spirituality with psychological well-being: Examining self-actualisation, meaning

    in life, and personal growth initiative. *Journal of Religion and Health*, *52*(3),

    915-929.

Irazabal, M., Marsa, F., Garcia, M., Gutierrez-Recacha, P., Matorell, A., Salvador-

    Carulla, L., & Ochoa, S. (2012). Family burden related to clinical and functional

    variables of people with intellectual disability with and without a mental

    disorder. *Research in Developmental Disabilities, 33*(3)*,* 796-803.

Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, cultural differences in the dementia caregiving experience: recent findings. *The Gerontologist, 41*(3), 334-347.

John, R., Resendiz, R., & De Vargas, L. W. (1997). Beyond familism?: Familism as explicit motive for eldercare among Mexican American caregivers. *Journal of Cross-Cultural Gerontology*, *12*(2), 145-162.

Kashdan, T. B., & Steger, M. F. (2007). Curiosity and pathways to well-being and meaning in life: Traits, states, and everyday behaviors. *Motivation and Emotion*, *31*(3), 159-173.

King, L. A., Hicks, J. A., Krull, J. L., & Del Gaiso, A. K. (2006). Positive affect and the experience of meaning in life. *Journal of Personality and Social Psychology*, *90*(1), 179-196.

Kilburn Jr, J. C. (1996). Network effects in caregiver to care-recipient violence: A study of caregivers to those diagnosed with Alzheimer's disease. *Journal of Elder Abuse & Neglect*, *8*(1), 69-80.

Kinney, J. M., & Stephens, M. A. P. (1989). Hassles and uplifts of giving care to a family member with dementia. *Psychology and Aging*, *4*(4), 402-408.

Kinney, J. M., Stephens, M. A. P., Franks, M. M., & Norris, V. K. (1995). Stresses and satisfactions of family caregivers to older stroke patients. *Journal of Applied Gerontology*, *14*(1), 3-21.

Kline, R. B. (2011). *Principles and practice of structural equation modeling*. New York, NY: The Guildford Press.

Knight, B. G., Silverstein, M., McCallum, T. J., & Fox, L. S. (2000). A social cultural stress and coping model for mental health outcomes among African American caregivers of Southern California. *Journal of Gerontology: Psychological Sciences, 3*(55), 142-150.

Kobasa, S. C. (1979). Stressful life events, personality, and health: an inquiry into hardiness. *Journal of Personality and Social Psychology*, *37*(1), 1-11.

Kottorp, A., Bernspång, B., & Fisher, A. G. (2003). Activities of daily living in persons with intellectual disability: Strengths and limitations in specific motor and process skills. *Australian Occupational Therapy Journal*, *50*(4), 195-204.

Krahn, G. L., & Drum, C. E. (2007). Translating policy principles into practice to improve health care access for adults with intellectual disabilities: A research review of the past decade. *Mental Retardation and Developmental Disabilities Research Reviews*, *13*(2), 160-168.

Kramer, B. J. (1993). Expanding the conceptualization of caregiver coping: The importance of relationship-focused coping strategies. *Family Relations*, *42*(4)*, 383-391.

Kramer, B. J. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist*, *37*(2), 218-232.

Krause, N. (2004). Stressors arising in highly valued roles, meaning in life, and the physical health status of older adults. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *59*(5), 287-297.

Laubmeier, K. K., Zakowski, S. G., & Bair, J. P. (2004). The role of spirituality in the psychological adjustment to cancer: A test of the transactional model of stress and coping. *International Journal of Behavioral Medicine*, *11*(1), 48-55.

Lawton, M. P., Moss, M., Kleban, M. H., Glicksman, A., & Rovine, M. (1991). A two-factor model of caregiving appraisal and psychological well-being. *Journal of Gerontology*, *46*(4), 181-189.

Lazarus, R. S., & DeLongis, A. (1983). Psychological stress and coping in aging. *American Psychologist*, *38*(3), 245-254.

Lazarus, R. S., & Launier, R. (1978). Stress-related transactions between person and environment. In L. A. Pervin, M. Lewis (Eds*), Perspective in international psychology* (pp. 287-327). New York, NY: Springer US.

Losada, A.*,* Márquez-González, M.*,* Knight, B. G.*,* Yanguas, J.*,* Sayegh, P.*, &* Romero-Moreno, R. (2010*).* Psychosocial factors and caregivers' distress: Effects of familism and dysfunctional thoughts. *Aging and Mental Health*, *14*(2)*,* 193–202*.*

Lee, E. E., Farran, C. J., Tripp-Reimer, T., & Sadler, G. R. (2003). Assessing the cultural appropriateness of the finding meaning through caregiving scale for Korean caregivers. *Journal of Nursing Measurement*, *11*(1), 19-28.

Levine, N. B., Gendron, C. E., Dastoor, D. P., Poitras, L. R., Sirota, S. E., Barza, S. L., & Davis, J. C. (1984). Existential issues in the management of the demented elderly patient. *American Journal of Psychotherapy*. *38*(2), 215-223.

Lim, Y. M., Luna, I., Cromwell, S. L., Phillips, L. R., Russell, C. K., & de Ardon, E. T. (1996). Toward a cross-cultural understanding of family caregiving burden. *Western Journal of Nursing Research*, *18*(3), 252-266.

Lin, J. D., Hu, J., Yen, C. F., Hsu, S. W., Lin, L. P., Loh, C. H., … & Wu, J. L. (2009). Quality of life in caregivers of children and adolescents with intellectual disabilities: Use of WHOQOL-BREF survey. *Research in Developmental Disability, 30*(6)*,* 1448-1458.

Lundqvist, L. O. (2013). Prevalence and risk markers of behavior problems among adults with intellectual disabilities: A total population study in Örebro County, Sweden. *Research in Developmental Disabilities*, *34*(4), 1346-1356.

Lundstrom, M., Astrom, S., & Graneheim, U. H. (2007). Caregivers' experiences of exposure to violence in services for people with learning disabilities. *Journal of Psychiatric and Mental Health Nursing, 14*(4), 338-345.

Maddi, S. R. (1967). The existential neurosis. *Journal of Abnormal Psychology*, *72*(4), 311-325.

Maes, B., Broekman, T. G., Dosen, A., & Nauts, J. (2011). Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability, 47*(6), 447-455.

Magaña, S. M. (1999). Puerto Rican families caring for an adult with mental retardation: role of familism. *American Journal on Mental Retardation, 104*(5), 466-482.

Magaña, S., Schwartz, S. J., Rubert, M. P., & Szapocznik, J. (2006). Hispanic caregivers of adults with mental retardation: Importance of family functioning. *American Journal of Mental Retardation*, *111*(4), 250–262.

McClintock, K., Hall, S., & Oliver, C. (2003). Risk markers associated with challenging behaviours in people with intellectual disabilities: A meta-analytic study. *Journal of Intellectual Disability Research, 47*(6), 405-416.

McCoach, D. B. (2003). SEM isn't just the schoolwide enrichment model anymore: Structural equation modeling (SEM) in gifted education. *Journal of Education For the Gifted, 27*(1), 36-61.

Melton, A. M., & Schulenberg, S. E. (2007). On the relationship between meaning in life and boredom proneness: Examining logotherapy. *Psychological Reports*, *101*(3), 1016-1022.

Menckel, E., Carter, N., & Viitasara, E. (2000). Violence toward caregivers of persons with developmental disabilities. *Work, 15*(1), 3-8.

Mendez-Luck, C. A., & Anthony, K. P. (2016). Marianismo and caregiving role beliefs among US-born and immigrant Mexican women. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *71*(5), 926-935.

Mikton, C., Maguire, H., & Shakespeare, T. (2014). A systematic review of the effectiveness of interventions to prevent and respond to violence against persons with disabilities. *Journal of Interpersonal Violence*, *29*(17), 3207-3226.

Muthén, L. K., & Muthén, B. O. (2012). *Mplus user's guide* (Seventh). Los Angeles, *CA:* Muthén & Muthén.

National Alliance for Caregiving and AARP. (2015). *Caregiving in the United States 2015*. Downloaded from http://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015.html.

Neary, S. R., & Mahoney, D. F. (2005). Dementia caregiving: The experiences of Hispanic/Latino caregivers. *Journal of Transcultural Nursing*, *16*(2), 163-170.

Noonan, A. E., & Tennstedt, S. L. (1997). Meaning in caregiving and its contribution to caregiver well-being. *The Gerontologist, 35*(6), 785-794.

Noonan, A. E., Tennstedt, S. L., & Rebelsky, F. G. (1997). Making the best of it: Themes of meaning among informal caregivers to the elderly. *Journal of Aging Studies*, *10*(4), 313-327

Noojin, A. B., & Wallander, J. L. (1997). Perceived problem-solving ability, stress, and coping in mothers of children with physical disabilities: Potential cognitive influences on adjustment. *International Journal of Behavioral Medicine*, *4*(4), 415-432.

Owens, G. P., Steger, M. F., Whitesell, A. A., & Herrera, C. J. (2009). Posttraumatic stress disorder, guilt, depression, and meaning in life among military veterans. *Journal of Traumatic Stress*, *22*(6), 654-657.

O'Leary, D., Jyringi, D., & Sedler, M. (2005). Childhood conduct problems, stages of Alzheimer's disease, and physical aggression against caregivers. *International Journal of Geriatric Psychiatry, 20*(5)*,* 401–405.

Paniagua, F. A., & Yamada, A. M. (Eds.). (2013). *Handbook of multicultural mental*

health: Assessment and treatment of diverse populations. San Diego, CA: Academic Press.

Parish, S. L., Seltzer, M. M., Greenberg, J. S., & Floyd, F. (2004). Economic implications of caregiving at midlife: comparing parents with and without children who have developmental disabilities. *Mental Retardation, 42*(6), 413-426.

Park, N., Park, M., & Peterson, C. (2010). When is the search for meaning related to life satisfaction? *Applied Psychology: Health and Well-Being, 2*(1), 1-13.

Park, N., & Peterson, C. (2009). Achieving and sustaining a good life. *Perspectives on Psychological Science*, *4*(4), 422-428.

Patnaik, A., Elliott, T. R., Moudouni, D. M., Fournier, C. J., Naiser, E., Miller, T. R., & Phillips, C. D. (2011). Severity of children's intellectual disabilities and Medicaid personal care services. *Rehabilitation Psychology*, *56*(4), 383-390.

Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., & Ruoppila, I. (2000). Life expectancy of people with intellectual disability: A 35-year follow-up study. *Journal of Intellectual Disability Research*, *44*(5), 591-599.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, *30*(5), 583-594.

Perkins, E. A., & LaMartin, K. M. (2012). The internet as social support for older carers of adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, *9*(1), 53-62.

Pinquart, M., & Sörensen, S. (2004). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: a meta-analytic comparison. *Aging & Mental Health*, *8*(5), 438-449.

Pruchno, R. A., & McMullen, W. F. (2004). Patterns of service utilization by adults with a developmental disability: type of service makes a difference. *American Journal of Mental Retardation*, *109*(5), 362-378.

Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., ... & Walter, S. D. (2004). Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*, *4*(1), 1-13.

Reece, D., Walz, T., & Hageboeck, H. (1983). Intergenerational care providers of non-institutionalized frail elderly: Characteristics and consequences. *Journal of Gerontological Social Work*, *5*(3), 21-34.

Redmond, B., & Richardson, V. (2003). Just getting on with it: Exploring the service needs of mothers who care for young children with severe/profound and life-threatening intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *16*(3), 205-218.

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting family caregivers in providing care. In R. G. Hughes (Ed.) *Patient safety and quality: An evidence-based handbook for nurses* (pp. 1-64). Rockville, MD: Agency for Healthcare Research and Quality.

Reker, G. T. (1994). Logotheory and logotherapy: Challenges, opportunities, and some empirical findings. *The International Forum for Logotherapy*, *17*(1), 47-55.

Reker, G. T., Peacock, E. J., & Wong, P. T. (1987). Meaning and purpose in life and

    well-being: A life-span perspective. *Journal of Gerontology*, *42*(1), 44-49.

Reker, G. T., & Wong, P. P. (1988). Aging as an individual process: toward a theory of

    personal meaning. In J. E. Birren & V. L. Bengston (Eds.), *Emergent theories of*

    aging (pp.134-173) Englewood Cliffs, NJ: Prentice Hall.

Resch, J. A., Benz, M. R., & Elliott, T. R. (2012). Evaluating a dynamic process model

    of wellbeing for parents of child with disabilities: A multi-method analysis.

    Rehabilitation Psychology, 57(1), 61-72.

Resch, J. A., Mireles, G., Benz, M. R., Zhang, D., Peterson, R. L., &

    Grenweldge, C. (2010). Giving parents a voice: A qualitative study of

    the challenges experienced by parents of children with disabilities.

    Rehabilitation Psychology, 55(2)*,* 139–150.

Reynolds, D. K. (1976). *Morita psychotherapy*. Berkeley, CA: University of California

    Press.

Rote, S. M., & Moon, H. (2016). Racial/ethnic differences in caregiving frequency: Does

    immigrant status matter? *The Journals of Gerontology Series B: Psychological*

    Sciences and Social Sciences. doi: 10.1093/geronb/gbw106

Rodrigue, J. R., Morgan, S. B. & Geffken, G. (1990). Families of autistic children:

    psychological functioning of mothers. *Journal of Clinical Child Psychology,*

    19(4), 371-379.

Ryden, M. B. (1988). Aggressive behavior in persons with dementia who live in the

    community. *Alzheimer Disease & Associated Disorders*, *2*(4), 342-355.

Ryden, M. B., Bossenmaier, M., & McLachlan, C. (1991). Aggressive behavior in

    cognitively impaired nursing home residents. *Research in Nursing & Health*,

    14(2), 87-95.

Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of

    psychological well-being. *Journal of Personality and Social Psychology*, *57*(6),

    1069-1081.

Sandvide A., Astrom S., Norberg A., & Saveman, B. I. (2004). Violence in institutional

    care for elderly people from the perspective of involved care providers.

    Scandinavian Journal of Caring Sciences, 18(4), 351-357.

Scannell, E. D., Allen, F. C., & Burton, J. (2002). Meaning in life and positive and

    negative well-being. *North American Journal of Psychology*, *4*(1), 93-112.

Scharlach, A. E., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. J. (2006).

    Cultural attitudes and caregiver service use: Lessons from focus groups with

    racially and ethnically diverse family caregivers. *Journal of Gerontological*

    Social Work, *47*(1-2), 133-156.

Scheerenberger, R. C. (1983). *A history of mental retardation*. Baltimore, MD: Brookes.

Schulenberg, S. E., Hutzell, R. R., Nassif, C., & Rogina, J. M. (2008). Logotherapy for

    clinical practice. *Psychotherapy: Theory, Research, Practice, Training*, *45*(4),

    447-463.

Schulenberg, S. E. (2003). Empirical research and logotherapy. *Psychological Reports*,

    93(1), 307-319.

Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation*, *38*(3), 195-206.

Seltzer, M. M., Greenberg, J. S., Floyd, F. J., Pettee, Y., & Hong, J. (2001). Life course impacts of parenting a child with a disability. *American Journal on Mental Retardation, 106*(3)*,* 265-286.

Siklos, S., & Kerns, K. A. (2006). Assessing need for social support in parents of children with autism and Down syndrome. *Journal of Autism and Developmental Disorders*, *36*(7), 921-933.

Smith, K. R., & Matson, J. L. (2010). Behavior problems: Differences among intellectually disabled adults with co-morbid autism spectrum disorders and epilepsy. *Research in Developmental Disabilities*, *31*(5), 1062-1069.

Steger, M. F. (2017). Meaning in life and wellbeing. In M. Slade, L. Oades, A. Jarden (Eds*), Wellbeing, recovery and mental health* (pp.75-78). New York, NY: Cambridge University Press.

Steger, M. F., & Dik, B. J. (2009). If one is looking for meaning in life, does it help to find meaning in work? *Applied Psychology: Health and Well‑Being*, *3*(1), 303-320.

Steger, M. F., & Frazier, P. (2005). Meaning in life: one link in the chain from religiousness to well-being. *Journal of Counseling Psychology*, *52*(4), 574-582.

Steger, M. F., Frazier, P., Oishi, S., & Kaler, M. (2006). The meaning in life questionnaire: assessing the presence of and search for meaning in life. *Journal of Counseling Psychology, 53*(1), 80-93.

Steger, M. F., & Kashdan, T.B. (2007). Stability and specificity of meaning in life and

life satisfaction over one year. *Journal of Happiness Studies, 8*(2), 161-179.

Steger, M. F., Kashdan, T. B., Sullivan, B. A., & Lorentz, D. (2008). Understanding the

search for meaning in life: personality, cognitive style, and the dynamic between

seeking and experiencing meaning. *Journal of Personality*, *76*(2), 199-228.

Steger, M. F., Kawabata, Y., Shimai, S., & Otake, K. (2008). The meaningful life in

Japan and the United States: levels and correlates of meaning in life. *Journal of

Research in Personality, 42*(3)*,* 660-678.

Steger, M. F., Oishi, S., & Kesebir, S. (2011). Is a life without meaning satisfying? The

moderating role of the search for meaning in satisfaction with life judgments. *The

Journal of Positive Psychology*, *6*(3), 173-180.

Sterritt, P. F., & Pokorny, M. E. (1998). African-American caregiving for a relative with

alzheimer's disease. *Geriatric Nursing*, *19*(3), 127-134.

Strand, M., Benzein, E., & Saveman, B. I. (2004). Violence in the care of adult persons

with intellectual disabilities. *Journal of Clinical Nursing*, *13*(4), 506-514.

Straznickas, K. A., McNiel, D. E., & Binder, R. L. (1993). Violence toward family

caregivers by mentally ill relatives. *Psychiatric Services*, *44*(4), 385-387.

Suelzle, M., & Keenan, V. (1981). Changes in family support networks over the life

cycle of mentally retarded persons. *American Journal of Mental Deficiency*,

83(3), 267-274.

Tenneij, N. H., & Koot, H. M. (2008). Incidence, types and characteristics of aggressive

behaviour in treatment facilities for adults with mild intellectual disability and

severe challenging behaviour. *Journal of Intellectual Disability Research*, *52*(2), 114-124.

Texas Department of Aging and Disability Services. (2015). *Home and community-based services (HCBS) provider resources*. Retrieved from http://www.dads.state.tx.us/providers/hcs/

Thompson, R. J., Gil, K. M., Abrams, M. R., & Phillips, G. (1992). Stress, coping, and psychological adjustment of adults with sickle cell disease. *Journal of Consulting and Clinical Psychology*, *60*(3), 433-440.

Trute, B., Benzies, K. M., Worthington, C., Reddon, J. R., & Moore, M. (2010). Accentuate the positive to mitigate the negative: Mother psychological coping resources and family adjustment in childhood disability. *Journal of Intellectual and Developmental Disability*, *35*(1), 36-43.

Tsai, S. M., & Wang, H. H. (2009). The relationship between strain and social support among mothers with intellectually disabled children. *Journal of Clinical Nursing*, *18*(4), 539-548.

United States Census Bureau. *Asians fastest-growing race or ethnic group in 2012, census bureau reports*. Retrieved from http://www.census.gov/newsroom/pressreleases/2013/cb13-112.html

Unwin, G., & Deb, S. (2011). Family caregiver uplift and burden: associations with aggressive behavior in adults with intellectual disability. *Journal of Mental Health Research in Intellectual Disabilities*, *4*(3), 186-205.

Valle, R., Yamada, A. M., & Barrio, C. (2004). Ethnic differences in social network

help seeking strategies among Latino and Euro-American dementia caregivers.
Aging & Mental Health, 8(6), 535-543.

Vladeck, B. C. (2003). Where the action really is: Medicaid and the disabled. *Health Affairs*, *22*(1), 90-100.

Wade, S. L., Taylor, H. G., Drotar, D., Stancin, T., & Yeates, K. O. (1996). Childhood traumatic brain injury: Initial impact on the family. *Journal of Learning Disabilities*, *29*(6), 652–661.

Wallander, J. L., & Varni, J. W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of Child Psychology and Psychiatry*, *39*(1), 29-46.

Wallhagen, M. I., & Yamamoto-Mitani, N. (2006). The meaning of family caregiving in Japan and the United States: A qualitative comparative study. *Journal of Transcultural Nursing, 17*(1), 65-73.

Wanless, L. K., & Jahoda, A. (2002). Responses of staff towards people with mild to moderate intellectual disability who behave aggressively: A cognitive emotional analysis. *Journal of Intellectual Disability Research*, *46*(6), 507-516.

Ware Jr, J. E., Kosinski, M., & Keller, S. D. (1996) A 12 item short form health survey: construction of scales and preliminary tests of reliability and validity. *Medical Care*, *34*(3), 220-233.

Weisz, V., & Tomkins, A. J. (1996). The right to a family environment for children with disabilities. *American Psychologist, 51*(12), 1239-1245.

Weston, R., Gore, P. A., Chan, F., & Catalano, D. (2008). An introduction to using

structural equation modeling in rehabilitation psychology. R*ehabilitation Psychology, 53*(3), 340-356.

White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *17*(3), 181-190.

Wikler, L., Wasow, M., & Hatfield, E. (1981). Chronic sorrow revisited: Parent vs. professional depiction of the adjustment of parents of mentally retarded children. *American Journal of Orthopsychiatry*, *51*(1), 63-70.

Winefield, H. R., & Harvey, E. J. (1994). Stress and family support as predictors of distress and rejection in people who care for a relative with schizophrenia. *International Journal of Stress Management, 1*(4)*, 283-298.

Winslow, B. W. (2003). Family caregivers' experiences with community services: a qualitative analysis. *Public Health Nursing*, *20*(5), 341-348.

Wong, P. T. (1997). Meaning-centered counseling: A cognitive-behavioral approach to logotherapy. *International Forum for Logotherapy, 20,* 85-94.

Worcester, J. A., Nesman, T. M., Mendez, L. M. R., & Keller, H. R. (2008). Giving voice to parents of young children with challenging behavior. *Exceptional Children, 74*(4)*, 509–525.

Yamamoto, N., & Wallhagen, M. I. (1997). The continuation of family caregiving in Japan. *Journal of Health & Social Behavior, 38*(2), 164-176.

Zeller, A., Hahn, S., Needham, I., Kok, G., Dassen, T., & Halfens, R. J. (2009). Aggressive behavior of nursing home residents toward caregivers: A systematic

literature review. *Geriatric Nursing*, *30*(3), 174-187.

Zika, S., & Chamberlain, K. (1992). On the relation between meaning in life and

psychological well-being. *British Journal of Psychology*, *83*(1), 133-145.