QUALITY OF LIFE AMONG FAMILY CAREGIVERS OF ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

By

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A DISSERTATION

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

Rehabilitation Counselor Education—Doctor of Philosophy

2016

ABSTRACT

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Caring for a family member with intellectual developmental disability (IDD) often results in many negative impacts, such as higher levels of stress and depression, physical and/or mental issues, lower level of support, lower financial capacity, as well as less positive or more pessimistic views of their child's future, and an overall lower level of perceived quality of life, compared to family caregivers of typically developed children. However, less attention has been given to family caregivers of adults with IDD, and non-parental caregivers (e.g., grandparents, siblings, cousins, and other relatives) are often excluded from those studies, despite that Quality of life (QoL) of family caregivers of children with IDD has been a popular research topic. In order to understand the caregiving experiences among family caregivers, the present study used a comprehensive conceptual framework to investigate the overall QoL of aging family caregivers of adults with IDD and how various physical, psychosocial, and health factors affected their perceived QoL. This study presents a broader and more comprehensive exploration of the QoL of family caregivers of adults with IDD, and contributes new knowledge to this group of caregivers. The result of this study can be used to provide further suggestions to the social care and welfare system about caregiver's special needs, and to extend the capacity of family caregivers to continue providing care without jeopardizing their own physical health, mental status, and overall QoL.

This dissertation is dedicated to my late grandparents

ACKNOWLEDGMENTS

I want first of all to thank all the members of my dissertation committee for their time and contribution: Dr. Connie Sung, Dr. Michael Leahy, Dr. John Kosciulek, Dr. Esther Onaga, and Dr. Gloria Lee. Without your expertise, guidance, and encouragement during the completion of this dissertation. Especially to Dr. Sung, you have taught me so much not only as a researcher but also as a mentor, thank you for guiding me along the way and never allow me to quit or have any pessimistic thoughts. I am so fortune to have the most cheerful, energetic, and the smartest advisor in the world.

I must also thank all the participants in my study. It would not have been completed without the support from all of the family caregivers of adults with IDD who used their own time to contribute to the survey. My heartfelt gratitude is also extended to College of Education for the funding support, so that I can return the favor to all the caregivers.

To my cohort: Jinhee, Annemarie, Jina, Rosemarie, Susan, Marwa, Trent, and my unofficial mentor, Dr. Kuo; thank you for all the wonderful memories and support given through all then seemed impossible moments. To my family, thank you for your love and emotional support, you have always believed in me on this journey, the trust and courage I gain from you are invaluable. To all my friends, thank you for your friendship and support in the countless days in MSU, your companion truly warmed up my life through all the snow storms and freezing cold winters! Special thanks to my husband, Andrew, I truly appreciate your unconditional love and sacrifice, you have been so supportive in every way possible, and have shown the patience over the years my study has taken. I would not have been able to get to this stage without you.

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CHAPTER 1

INTRODUCTION

This chapter presents an overview of characteristics of parents of children with intellectual and developmental disabilities (IDD), and the research gap of the caregiving experiences of family caregivers of adults with IDD. The following sections will include statement of problem, purpose of the study, research questions, rationale for the hypotheses, and the significant of the study.

Statement of Problem

A series of studies have focused on caregivers' quality of life of children with intellectual and developmental disabilities (IDD); however, much less attention has been given to family caregivers of adults with IDD. According to the Center of Disease Control and Prevention (CDC), one in six children in the United States, or 15% of children aged 3 to 17 years old, are diagnosed with one or more developmental disabilities, such as autism spectrum disorder (ASD), cerebral palsy (CP), intellectual disability (ID), Down syndrome, Rett syndrome, epilepsy, and other developmental delay conditions (CDC, 2015). These developmental disabilities are conditions that may involve long-term physical and mental impairments, and they are usually life-long symptoms that require special and intense care. Caregivers of children with IDD often report higher levels of stress and depression, physical and/or mental issues, lower level of perceived quality of life, lower level of support, lower financial capacity, and lower social status, as well as less positive or more pessimistic views of their child's future (Abbeduto et al., 2004; Allik, Larsson, & Smedje, 2006; Blankenship, 2009; Browne & Bramston, 1998; Brown, Anand, Fung, Isaacs, & Baum, 2003; Caldwell, 2008; Chou, Lin, Chang, & Schalock, 2007; Lee et al., 2009; Lin, Orsmond, Coster, & Cohn, 2011; Mugno, Ruta, D'Arrigo, & Mazzone, 2007). Parents with children with CP also have reported suffering from poor physical and emotional health, such as back pain, migraine headaches, stomach aches, and depressive symptoms (Murphy, Christian, Caplin, & Young, 2007).

Clearly, a caregiver's health and well-being are highly related to their child's disability and functional level. Physical and psychological well-beings, as Felce and Perry (1995) argued, are all part of an overall construct: Quality of Life (QoL). QoL is defined by the World Health Organization (WHO) as an individual's perceived level of physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to important features of their environment (Billstedt, Gillberg, & Gillberg, 2011; Chou et al., 2007; Mugno et al., 2007; World Health Organization, 1996; Yoong & Koritsas, 2012). Felce and Perry (1995) defined QoL as a multidimensional concept, which consists of physical well-being, material well-being, social well-being, development and activity well-being, and emotional well-being. Some previously established conceptual models for investigating caregivers of individuals with disability did not include other aspects of well-being, except for physical and psychological well-being (e.g., Armstrong, Birnie-Lefcovitch, & Ungar, 2005; Jan Blacher, 2001; Raina et al., 2004). However, having a family member with a disability is not the only factor affecting one's physical and psychological well-being; other aspects of well-being should also be considered since all of the constructs might have interrelationships among one another within the family and environmental context. Since there is a growing number of empirical studies indicated that caregivers of people with disability report having lower QoL than the general population, it is necessary to advance our knowledge about and understanding of the perceptions of QoL.

The demographics in the United States are changing. According to the Census report, the number of individuals aged 65 years and above is expected to rise from 8.1% in 2004 to almost 21% by 2050 (cited by Heller, Caldwell, & Factor, 2007). People with IDD also live longer because of medical advances and improved living conditions, with the average age of death ranging from the mid-50's to the early 70's, depending on the severity and the type of disability (Heller & Arnold, 2010). Despite of the abundance of data on children with IDD, the estimate of the number of adults with IDD is inconsistent across different service providers' reports, and it is estimated to range from 0.5% to 2.5% of the general population (Bethesda Institutes, n.d.). Heller and Factor (2004) estimated that there were 641,000 adults aged 60 or above who had IDD in the US, and the number would be double to 1,242,794 by the year 2030.

As the prevalence of IDDs continues to rise, it is expected that more people with IDD will be residing with their parents even after they transit into adulthood. For example, Anderson, Shattuck, Cooper, Roux, and Wagner (2005) noted that young adults with ASD and low functional skills may co-reside with parents longer, due to higher support needs and care demands in daily life. According to several earlier studies, most adults with intellectual disability (ID) would live with their parents even after their transition age to adulthood, and often stay until the parents become no longer capable to take care of them, or until the parents pass away (Essex, Seltzer, & Krauss, 1999a; Fujiura, 1998; Hayden & Heller, 1997). Chou, Lee, Lin, Kröger, and Chang (2009) also pointed out that for some of the caregivers of adults with ID, the caregiving task might last more than 50 years. In fact, Fujiura (1998) estimated that 60% of people with ID continue to live with their parents after they are in adulthood.

Recent studies also showed similar outcomes. For example, Anderson et al. (2005) surveyed 620 young adults with ASD and found out that after leaving high school, comparing to their counterpart with other disabilities, these young adults with ASD were significantly more likely to live with parents or guardians, and less likely to live independently. Caldwell (2008) pointed out that an even higher co-residence rate: about 85% of people with IDD continued to live with their parents even after they become adults. Additionally, in a more recent study, Seltzer, Floyd, Song, Greenberg, and Hong (2011) pointed out that more than one third (39%) of adult participants with ID and IDD in their study continued to live with their parents when the parents were in their 60s. According to the National Longitudinal Transition Study-2, researchers found that young adults with all types of disabilities were less likely to be living independently compared to their peers in the general population (45% vs. 59%). Among those young adults with IDD, only 17% of young adults with ASD and 36% of young adults with IDD have lived independently at some point up to eight years after graduating from high school (Newman et al., 2011). Although the number of young adults with IDD who have lived independently is still unknown, based on previous research and numbers it is fair to infer that the rate would be relatively low compared to their typically developed counterparts.

Parents usually take the primary responsibilities to provide care and support to their adult children with IDD; even if their adult children have moved out, these aging parents still stay involved and maintain part of their caregiving responsibility (Ben-Zur, Duvdevany, & Lury, 2005; Essex et al., 1999a; Krauss, Seltzer, & Jacobson, 2005; Raina et al., 2004). Given that both the caregivers and the people with IDD have longer life expectancies, parents of adults with IDD are expected to provide caregiving tasks longer; it is also expected that these aging parents need to balance their non-parental tasks (such as employment) and their own interests (Yoong & Koritsas, 2012), and deal with their own declining health conditions (Boerner & Reinhardt, 2003) at the same time. Seltzer et al. (2004) found that when aging caregivers co-reside with adult children with IDD for a long time, they showed significant increase in depressive symptoms and poorer health related QoL, which means that long term co-residence could have a huge impact on the caregivers' psychological well-being. Thus, it is important to understand the aging caregivers' overall QoL, in order to tailor services to their special needs, especially when they have to take the primary caregiver role for their adult children with IDD and to struggle with their own health conditions in their early years of old age at the same time.

Among caregiver research studies, coping strategies and degree of social support have been found to be predictive of caregivers' well-being, and may buffer the effects of stressors on family adaptation (Lin et al., 2011). For example, Raina et al., (2004) examined 20 studies which focused on the well-being of parents of children with disabilities, and identified that social support was related to higher maternal psychological adjustment, and that social support can mediate the well-being of the parents and the relationship between stressors and outcomes. Social support can also predict family adjustment, associated with mental health and social functioning. Seltzer, Greenberg, Floyd, and Hong (2004) indicated that caring for adult children with IDD or mental health problems is a risk factor that may elevate the possibility of physical and psychological issues; yet coping and social support are protective factors that can buffer the negative impact in this situation of caregivers

Coping, as Armstrong et al. (2005) defined, is a complex interaction between the individual and the environment, with the goal of managing the stressors within the environment. Lazarus and Folkman (1984) proposed two categories of coping: problem-focused and emotion-focused coping. Problem-focused coping strategies are cognitive and behavior-focused approaches that are aimed to solve the problems or manage the stressors; emotion-focused coping, on the other hand, include efforts to reduce or handle emotional stress (Benson, 2010). In the context of caregivers, past studies have shown that among family caregivers of individuals with ASD and ID, the use of emotion-focused coping strategies was found to be associated with higher levels of psychological stress; whereas the use of problem-focused coping strategies were often identified to be helpful in improving caregivers' psychological well-being (Abbeduto et al., 2004; Benson, 2010). Furthermore, Seltzer et al. (2011) believed that despite all of the aforementioned negative impacts, most of the parents of children with IDD showed patterns of resilience and effective coping strategies with parenting obligations.

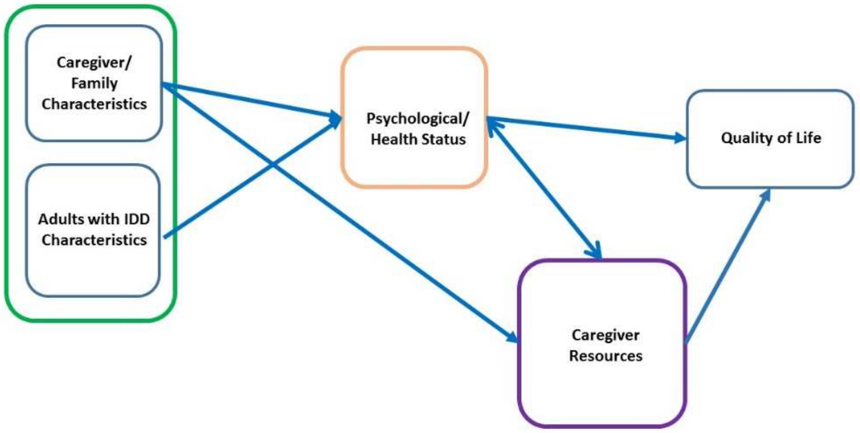
Previous studies indicated that parents of children with IDD reported having decreased contact with friends, and having limited social network to only include other families with children with the same disability(Haley & Perkins, 2004a; Stuart & McGrew, 2009). In this study, parents of children with IDD also had higher risks facing social isolation situations, reduced participation in social events, and decline in social support over time. However, social support has been found to be associated with positive outcomes on caregivers. For example, Seltzer et al. (2004) indicated that both social support and coping strategies were protective factors in terms of maintaining the resilience of individuals. Raina and the colleagues (2004) also concluded from many previous studies that caregivers who have high social support can manage better in difficult situations than those who have lower social support. Feldman et al. (2007) found that social support can potentially buffer a caregiver's depressive symptoms. In conclusion, social support and coping strategies can buffer the effects of stressors and reduce negative outcomes (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001); social support and coping strategies also have been identified as important predictors of stress reduction (Raina et al., 2004).

After reviewing 20 studies of caregivers' health outcomes, Raina et al. (2004) identified several factors that were related to caregiver's well-being, such as the caring demands of the child with a disability, the child's level of function, the residence of the child, marital satisfaction, and the availability of social support. Therefore, to understand caregiver's well-being requires researchers to explore with multiple factors because a single linear model does not serve the purpose to gain advance knowledge of such a complex construct. In other words, it is important to use a multi-dimensional conceptual framework which includes several other constructs in order to understand the well-being of caregivers from a broader perspective.

Raina et al. (2004) proposed a multidimensional model to guide research in the field of caregiver health, specifically in the pediatric area. The model is built upon previous research and theory, which includes five constructs: background and context, child characteristics, caregiver strain, intrapsychic factors, and coping/supportive factors and health outcomes. Raina and colleagues believe that caregiving happens in the context of the caregiver's social and economic status, and the economic capacity of the family is related to available resources and caregiving burdens. Thus, a caregiver's *background and contextual* variables, which include socioeconomic status, is the first factor to be considered. The second construct is *child characteristics*, including disability of the child and the child's behavioral problems, which are believed to be associated with caregiver health. The third construct, *caregiver strain*, is about the caregiving demands of the child with a disability, the conflict between the daily demands for care with the caregiver's occupational role, and the perception of formal care. *Caregiver intrapsychic factors* refer to the caregiver's internal state, for example, the caregiver's self-esteem and the sense of mastery over the caregiving tasks. The last construct of the model is *coping/supportive factor*, which includes social support, family function, and stress management; and all of these factors that are under the fifth construct are related to the caregivers' health outcomes.

However, this conceptual framework was originally developed to be applied to caregivers of children with disability, especially for children with cerebral palsy; yet for the present study, the researcher is interested in knowing whether the model is applicable to caregivers of adults with disability. The aforementioned model is further modified to test the four research questions below. Figure 1 depicts a conceptual model for describing the pathways between a family caregiver's personal and family characteristics (e.g., age, gender, marital status, and socio-economic status), adults with IDD's characteristics (e.g., functional independence level, behavioral problems), as well as caregivers' strains (e.g., caregiver's physical/psychological issues) and resources (e.g., coping strategies and social support). The outcome of this model is the overall QoL of the caregivers, including physical and psychological well-being. The domains describe the key variables in the present study that might affect family caregivers' overall level of QoL. This model will be explained in detail in Chapter 2.

Figure 1: Proposed conceptual framework



Since the majority of adults with IDD tend to stay with their family members, it is crucial to understand the caregivers' perspective and their needs. To explore the subjective caregiving process for a family member with a disability, Hayden and Heller (1997) suggested that the influence of the aging process should be considered to understand the family's caregiving experiences with an adult member with IDD because the perception or the effect that life-long caregiving responsibility has on the QoL might have changed over the course of time. How well these aging caregivers cope with the challenges and stresses of caregiving may be an important determinant of their well-being, and it is therefore the focus of the present investigation. Two different models were mentioned by researchers when discussing caregiver's well-being over life: the wear and tear hypothesis, and the adaptation model (Caldwell, 2008; Hayden & Heller, 1997). The former suggests that aging caregivers are less supported, more isolated, and experience more stress over time. In contrast, the latter one believes that because of increasing stability, decreasing behavioral issues, greater acceptance of the family member with disability, and greater support from that individual, aging caregivers can become more experienced and can adjust better to their caregiving role. Some of the researchers believe that after a couple of decades of caring for their adult children with disability, caregivers will develop a sense of mastery, and thus they will have higher levels of satisfaction and better quality of life (Heller et al., 2007; Taylor, 1983; quoted by Seltzer, 1995).

Adult years can also be a stressful time for both the adults with IDD and the caregivers, which is usually a time for typically developed young adults to move out of the family home and to start to becoming independent (Blacher, 2001; Krauss et al., 2005). During this "launching period," parents with young adults with IDD often do not experience this stage until much later (Krauss et al., 2005). Generally, society expects young adults to move out and live independently, which are signs of successful transition into adulthood. Additionally, previous studies have consistently indicated that individuals with IDD are less likely to live independently (Anderson, Shattuck, Cooper, Roux, & Wagner, 2014; Billstedt, Gillberg, & Gillberg, 2005). In addition to the turbulence in the transition period, adults with IDD have also lost their entitled services, and the search and advocacy for the services can be add-on stressors to the family caregivers.

Although there is increasing research focusing on caregivers of children with IDD, how caregivers of adults with IDD are affected by the caregiving demands is less studied. Since family caregivers of adults with IDD provide life-long caregiving tasks, it is important to understand caregivers' perspectives on their continuous challenges and needs of taking care of an adult family member with IDD. How they cope with all these life stages as they continuously provide care for adults with IDD continuously, and how these caregiving demands affects their own QoL, are critical to be understood in order to provide better and responsive services for individuals with IDD and their families.

Purpose of the Study

The primary purpose of this study is to investigate the overall QoL of aging family caregivers of adults with IDD and how various physical, psychosocial, and health factors affect their perceived QoL. Several predictor variables are identified, which include (1) family demographic variables: caregiver's age, gender, race/ethnicity, education level, marital status, employment status, family annual income, and caregiver role; (2) adults with IDD characteristics: age, diagnosis, functional independence level, behavioral issues, residential status, and employment status; (3) caregiver's physical and mental health; and (4) family resources: coping strategies and social support. Measures used in this study are intended to provide a comprehensive picture of caregiver's QoL, which use a conceptual model adapted from three conceptual frameworks by Armstrong et al. (2005), Blacher (2001), and Raina et al., (2004). Within this modified model, the caregiver's QoL will be examined from several perspectives, such as personal and environmental characteristics. This study will also explore the experiences of caregivers with respect to the residential and employment status of their family member with IDD, and his/her independence level and behavioral aspects. Results from the current study will serve the purpose of establishing responsive services and support to aging family caregivers so that they can continue to provide care without sabotage their own physical and psychological well-being, as well as their overall QoL. The information obtain from this study will be critical to service providers to design and develop effective services for not only adults with IDD, but also their caregivers. Specific instruments will be used based on how pertinent they are to the areas assessed and their relevance to this present study.

Research Questions

The specific research questions that are addressed include:

Research Question #1: What are the relationships among demographic variables, psychological/health factors (depression, perceived stress, and physical health), caregiver resources (i.e., coping strategies, social support), and QoL among aging family caregivers of adults with IDD? For this research question, it is hypothesized that demographic variables and psychological/health factors, caregiver resources, are related to QoL among family caregivers of adults with IDD.

Research Question #2: How well does the modified conceptual framework predict QoL of aging family caregivers of adults with IDD? For this research question, it is hypothesized that the modified conceptual framework will account for a significant amount of variance in the QoL of family caregivers of adults with IDD.

Research Question #3: Do the caregivers' mental health status (i.e., depressive symptom and perceived stress level) mediate the relationship between adults with IDD's behavioral issues and psychological aspect of QoL among family caregivers of adults with IDD? For this research question, it is hypothesized that both depressive symptom and perceived stress level will respectively partially mediate the relationship between adults with IDD's behavioral issues and psychological health among family caregivers of adults with IDD. In other words, it is hypothesized that having a less depressing and less stressful mental health status will improve family caregiver's QoL even if they are providing care to adults with IDD who show more behavioral issues.

Rationale for the Hypotheses

It is hypothesized that the modified conceptual framework proposed in this study would successfully predict the overall QoL of aging family caregivers of adults with IDD. As Raina et al. (2004) pointed out, a well-structured conceptual framework is required to understand the complex nature between the direct and indirect relationships that impact the health and well-being of family caregivers.

Specifically, first, it is hypothesized that, demographic variables (both caregiver and the care recipients) are related to the QoL among aging family caregivers of adults with IDD. Some of the demographic variables include in the present study are age, gender, education level, annual household income, care recipient's type of disability, and independence level. Caregiver's age has been recognized as relevant to caregiver's mental health (Hayden & Heller, 1997), and their caregiver role (mother or father) has also been associated with the psychological attitude and coping strategies used toward the individuals with IDD (Essex et al., 1999a). Raina et al. (2004) concluded from several early studies that caregivers' socio-economics status, age, and marital status were related to the psychological health of the caregivers. Moreover, Raina and colleagues also identified that behavior problems, level of functioning, age, and gender of the child with disability, as well as severity of the disability, were all proved to be linked to parental stress. Past research has also shown that the type of disability and co-residence can lead to different mental health outcomes (Esbensen & Seltzer, 2011; Krauss et al., 2005). Based on these previous results, it is hypothesized that both demographic variables of caregivers and adults with IDD are related to the overall level of QoL.

Secondly, it is hypothesized that family caregivers' coping strategies, perceived social support, and physical and psychological factors are related to the QoL among aging family caregivers of adults with IDD. Several earlier studies have identified that these constructs are related to the level of QoL among family caregivers. For example, both coping strategies and social support have been identified as protective factors for caregivers (Heller et al., 2007). Abbeduto et al. (2004) found that mothers of children and adolescents with Down syndrome tended to utilize more problem-focused coping and less emotion-focused coping, which correlated with the effectiveness of buffering the negative impact of providing caregiving tasks. In contrast, mothers who used more emotion-focused coping strategies were more likely to have higher levels of psychological stress. Previous studies have also shown that the more accessible social support the caregivers have, the more active coping strategies, and the greater family cohesion, would lead to lower caregiving burdens and less stress-related health issues and depressive symptoms (Dunn et al., 2001; Heller et al., 2007). Similarly, Ben-Zur et al. (2005) studied mothers of adults with IDD and found that regardless of the residential status of their adult children, social support was strongly related to mothers' mental health status. Besides, other constructs that were related to the level of QoL were also recognized. For instance, caregivers of children with IDD often reported having various health and psychological issues, such as higher level of stress and depression, less positive or more pessimistic views of their child's future, poor emotional health, back pain, migraine, and stomach aches (e.g., Abbeduto et al., 2004; Blankenship, 2009; Caldwell, 2008; Chou et al., 2007; Lee et al., 2009; Mugno et al., 2007; Murphy et al., 2007).

Thirdly, it is hypothesized that depressive symptoms and perceived stress level would mediate the relationships between adults with IDD's behavioral issues and caregiver's psychological health and QoL among family caregivers of adults with IDD. Previous studies have shown that caregivers for adults with IDD might express higher depressive symptom and stress level. For example, Seltzer et al. (2004) found that aging caregivers who co-reside with adult children with IDD for a long time reported having significant increase in depressive symptoms and poorer health related QoL. Previous studies have also shown that caregivers can experience stress from many sources, such as their own health issues, future planning for the individuals with disabilities (Chou et al., 2011; Dillenburger & McKerr, 2010).

Significance of the Study

Although there is abundant literature focusing on parents of children with IDD and their QoL, less attention has been given to the long-term experiences and outcomes for family caregivers of adults with IDD (Lakin & Stancliffe, 2007). Moreover, the majority of previous research only focused on some aspects of caregiving experiences, such as coping strategies, social support, or physical/psychological well-being. However, research that has examined the full range of those crucial aspects and their interactions is very limited.

This study will serve the purpose presenting a broader and more comprehensive exploration of the QoL of family caregivers of adults with IDD. The lack of understanding of the needs among this group of caregivers makes it difficult to provide suitable services and to locate resources for them. Therefore, this study is intended to be significant in various respects. First, caring for an adult with IDD might have significant impacts on caregivers' overall QoL, such as physical and/or mental well-being. With the increasing longevity of the population, it is crucial for rehabilitation professionals to address the issues faced by family caregivers who provide care to their adult with IDD. The findings of this study can advance our knowledge of how lifelong caregiving experiences influence aging caregivers' QoL. Second, the extended understanding of this caregiving population can also provide further suggestions to the social care and welfare system about their special needs, so as to extend the capacity of family caregivers to continue to provide care without jeopardizing their own physical health, mental status, and overall QoL (Seltzer, Floyd, Song, Greenberg, & Hong, 2011). Third, the results of this study are proposed to be able to improve the level of QoL of both caregivers and care recipients. Family caregivers sometimes are expected to provide life-long care to adults with IDD. Adults with IDD's level of QoL might be affected by their caregivers' overall well-being. To conclude, this study will not only be the first step of understanding the QoL of family caregivers of adults with IDD, but also provide suggestions for how to best meet the needs of caregivers by establishing suitable interventions for families of adults with IDD, and thus supporting families with appropriate resources.

CHAPTER 2

LITERATURE REVIEW

This chapter will provide a comprehensive review of the current literature relating to the topics associated with the variables of interest of the present study, and inform the research design. Specifically, the impacts of caring for individuals (children or adults) and how demographic variables affect QoL on the caregivers will be discussed. Three conceptual frameworks and a modified conceptual framework which will be used for the present study will be provided to better understand the present study and the possible interactions among variables.

The purpose of this study is to examine the Quality of Life (QoL) in a sample of family caregivers of adults with intellectual and developmental disabilities (IDD). This study will be done within the conceptual framework of describing the pathways between QoL and caregivers' personal characteristics and environmental factors, adults with IDD's functional independence level, and caregivers' strains and resources.

Terminology and Definition of Developmental Disabilities

To use appropriate terms to describe people with disabilities has always been an issue. In the 19th century, when people with disabilities were generally institutionalized, the word "idiot" was often used to describe people with developmental disabilities (Garfin, 2004). With the rise of disability awareness, these terms were replaced with more appropriate ones. One notable change recently is that the term "mental retardation" was eliminated from the International Classifications of Diseases 11th revision (ICD-11), and the fifth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) had also adapted it. Originally, mental retardation was used to replace other terms such as "feeblemindedness" and "idiocy," while now it has been replaced by intellectual disabilities, to reflect disability awareness, as well as its impact on the individual's functioning, and to encourage for a more comprehensiveness assessment process (Harris, 2013).

The current definition of developmental disabilities under the Developmentally Disabled Assistance and Bill of Rights Act is that they are severe, chronic conditions of an individual that may have long-term physical and mental impairments which are likely to continue indefinitely, and are manifested before the age of 22. These impairments in physical, learning, language, or behavior areas could result in substantial limitations on major life activities, such as self-care, learning, and capacity for independent living, and they usually last through an individual's lifetime (Administration for Community Living, 2013; CDC, 2015). Most common examples of IDD include autism spectrum disorder (ASD), cerebral palsy (CP), intellectual disability (ID), fragile X, Traumatic Brain Injury (TBI), Down syndrome, Rett syndrome, epilepsy, and other developmental delay conditions.

Impact of Caring for Adults with IDD on Caregivers

Caring for Adults with Developmental Disabilities

Just like the general public, people with IDD nowadays have increased longevity because of advancements in the medical field and improved living conditions. Their average age of death ranges from the mid-50's to the early 70's, depending on the types and the severities of their disabilities (Heller & Arnold, 2010). Braddock et al. (2011) estimated that around 71% of individuals with IDD live with a family caregiver. Chou et al. (2009) noted that the caregiving task could last for more than 50 years for some of the caregivers of adults with intellectual disabilities. As this population lives longer and ages, it is expected that there will be higher co-residency rates between adults with IDD and their parents or other family members. The increased longevity also means that adults with IDD now require longer periods of time for services than in the past. Aging parents must develop care plans for their adult children with IDD, to ensure that they will be well taken care of when the parents are no longer capable of providing care (Parish & Lutwick, 2005). However, continuously worrying about the future plans of their adult children with IDD could increase their anxiety and result in higher stress levels (Dillenburger & McKerr, 2010).

Types of disability can be viewed as a predictor of the residential status of adults with disabilities. Based on the National Longitudinal Transition Study-2, the rates of living independently after graduating from high school were significantly higher for young adults with learning disabilities, speech/language and hearing impairments, emotional disturbances, visual impairments, and other health impairments, than those young adults with orthopedic impairments, ASD, multiple disabilities, or deaf-blindness (Newman et al., 2011). Different diagnoses also matter in terms of the caregivers' perceived life satisfaction. For instance, maternal caregivers of adults with Down syndrome were found to be less burdened compared with mothers of adults with intellectual disabilities (Seltzer, Krauss, & Tsunematsu, 1993).

In addition, type of disability can affect individuals with IDD's relationships with their siblings without disabilities, and thus may result in whether the siblings without disabilities will take over the caregiver role after the parents are not able to. Compared to siblings of adults with ASD, siblings of adults with Down syndrome reported having closer relationships and were more optimistic about their relationships and the adult with Down syndrome's future (Heller & Arnold, 2010). Siblings are also often a source of support for parents of people with disabilities. Caldwell (2008) pointed out that support from siblings of people with IDD was associated with aged parents' well-being. Siblings of adults with IDD also tend to take over the primary caregiver role when the parents can no longer provide care because of their age, retirement, or death (Heller & Arnold, 2010). After reviewing 23 research articles focusing on siblings of people with IDD, Heller and Arnold (2010) concluded that parents often had expectations for the siblings to be the future primary caregiver or guardian for their brother or sister with IDD, and the siblings themselves were expecting to co-reside with their brother or sister with IDD someday. Most of these siblings tended to report having close relationships, having positive impacts on their lives and health, and feeling emotionally supported by their brother or sister with IDD. Overall, siblings tend to take on future caregiver roles, and they will continue to have long lasting relationships with their siblings with IDD. They also usually have positive perceptions of having a sibling with IDD and positive psychological outcomes after taking over the caregiver role.

Overall physical health. Murphy, Christian, Caplin, and Young (2007) indicated that lack of time, lack of respite care, and lack of qualified service create another layer of stress to caregivers that caregivers reported that caring for their own health needs is their lowest priority, since the majority of their time was dedicated to caring for other family members. When exploring the health status of caregivers for children with disabilities, Murphy et al. (2007) found that nearly all caregivers participating in their study reported having their physical and emotional health negatively impacted by the caregiving demands, such as back and shoulder pain due to lifting their children. The caregivers often neglected their own health conditions, but put their family member as the first priority in their lives instead(Haley & Perkins, 2004; Yamaki, Hsieh, & Heller, 2009). Also, greater heart disease rate, poorer immune function, and lower perceived health status were found among both genders of family caregivers of people with disabilities (Heller et al., 2007). Chou et al. (2011) also confirmed with their study results that aging female caregiver's subjective and objective burdens could be predicted by the caregiver's health status. Despite a number of chronic health conditions that have been found to be associated with aging female caregivers, studies have found that their perceived health-related QoL might be as good as or even better than that of women in the general population (Yamaki et al., 2009). The reasons might be that female caregivers often adjust their own lifestyles in response to the need of care recipients with IDD, and one of the outcome of the adjustment is the positive perception of their own health (Marsha Mailick Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001; Yamaki et al., 2009). However, Seltzer et al. (2011) found that parental caregivers of individuals with IDD overall have experienced poorer physical health, compared to parents of individuals without disabilities.

Overall mental health. A caregiver's health condition is usually associated with stress (Raina et al., 2004). Unlike caregivers of other family members, caring for children with chronic disabilities is often intensive, and it can negatively impact the family's functioning and can last for many decades (Higgins, Bailey, & Pearce, 2005). Higgins, Bailey, and Pearce (2005) concluded from several past research studies that the stress associated with caring for children with ASD often impacts several aspects of family functioning, such as recreational activities, household chores, finances, physical and psychological issues, marital satisfaction, sibling relationships, and relationships with relatives and friends. It has been called the "unexpected journey," or "informal caregiver career," to care for a child with a disability, since they will face multifaceted, complicated, and stressful lives (Murphy et al., 2007; Raina et al., 2004), and also the "full-time" responsibility to provide long-term care and to become a life-long caregiver (Haley & Perkins, 2004a; Serrata, 2012).

Depressive symptoms were found to be common among mothers of children with IDD, especially among mothers of children with ASD compared with children with ID (Feldman et al., 2007). According to Feldman et al. (2007), the explanation of the difference between the groups is that unlike children with ID, the diagnosis of ASD usually comes later, and the uncertainty and depressive symptoms may develop when parents learn that their child has ASD, after the child has typically developed for a few years. Abbeduto et al (2004) found that mothers of adolescents and young adults with ASD reported significantly higher levels of depressive symptoms than did mothers of individuals with Down syndrome. Although there were group differences among disability types, past research has widely recognized that financial issues, poor physical and psychological health, and isolated social situations are associated with caring for children with IDD, and result in poorer QoL (Heller, Caldwell, & Factor, 2007; Higgins et al., 2005; Murphy et al., 2007). Maternal depressive symptoms have been recognized to be largely correlated with behavioral problems in children with ASD (Feldman et al., 2007).

Serrata (2012) also concluded that there are several stressors and depression symptoms that are related to parental stress when caring for children with ASD: child's social skill deficits, sleep disturbance, and familial, marital, and financial stress. The author further recognized that to juggle between work and family responsibilities can result in parents’ depressive symptoms, and learned helplessness is the outcome of multiple stressors of caring for children with ASD (Serrata, 2012). Other researchers also found the similar patterns. For example, financially, caring for children with a disability commonly is more costly than caring for children without a disability (Dillenburger & McKerr, 2010), families of people with IDD were found to be less financially secure than general families (Fujiura, 1998), and caregivers also have reported financial impacts, such as lower employment rates and overall low socioeconomic status

(Caldwell, 2008; Greenberg, Seltzer, & Greenley, 1993; Heller et al., 2007; Raina et al., 2004; Seltzer et al., 2011). These caregivers often have multiple roles in their lives, such as occupational roles and family roles, on top of their caregiving role, which can result in additional stress and will require rearrangement of many priorities (Raina et al., 2004). Serrata (2012) further pointed out that although mothers of children with ASD have reported having more work intrusions due to responding to caregiving demands, they spend equal number of work hours as mothers of typically developed children, which could result in higher levels of fatigue. Generally, the severity of the disability, behavioral issues, and the functional level can all relate to caregiver burden when caring for people with IDD (Chou, Fu, Lin, & Lee, 2011). Furthermore, constantly worrying about the future of their adult children with disabilities can be additional emotional stressors that increase anxiety levels, on top of their own deteriorating health, bereavement, as well as physical and emotional tiredness (Dillenburger & McKerr, 2010; Murphy et al., 2007)

The functional level of children with IDD, or the independence level of the adults with IDD, is also a predictor of a caregiver's overall health status. The three most stressful factors related to raising children with ASD are (1) the life-long condition, (2) lack of acceptance in society and from other family members, and (3) receiving less support and resources from health care and other social services (Sharpley et al., 1997; as cited in Higgins et al., 2005). Often times the lower functioning of children with IDD, the greater demands they require, such as longer caring hours and needs for assistance with personal care (Caldwell, 2008; Greenberg et al., 1993; Heller et al., 2007), which can also lead to higher level of caregiver burden. As Higgins, Bailey, and Pearce (2005) stated, stress is especially related to the severity of behavioral issues for children with ASD, and family functioning is usually impacted by their behavioral problems, the child’s dependency, and the limits imposed on family activities. Chou et al. (2011) further indicated that the care recipient’s level of instrumental ADL could also be a strong predictor of aging female caregiver’s objective level of burden. Additionally, the researchers also found that ADL functionality was the only predictor in predicting caregiver objective burdens (Chou et al., 2011).

Although states and local agencies provide various services to people with IDD, such as respite care, employment placement, personal assistance, mental health care, and behavioral management, previous reports have shown that only a very small percentage (10%) of people of IDD are receiving such services (Parish & Lutwick, 2005). Additionally, the increase the longevity of people with IDD also lead to smaller family size and longer distances between extended family members, increased women’s participation in the labor force, and growing governmental fiscal constraints, all of which affect the caregiver experiences and increase the reliance on family caregivers to provide care (Heller et al., 2007; Parish & Lutwick, 2005).

Psychosocial adjustment of aging caregiver. Parents of children with IDD often reported poorer psychological adjustment than parents of typically developed children, such as higher stress level, and greater risk of marital distress and divorce (Seltzer et al., 2011). However, despite the fact that most of the research has been focusing on negative outcomes of having a family member with disabilities, family caregivers often also have reported feeling rewarded psychologically and having a sense of contentment from providing care to their family members with disabilities (Baker & Blacher, 2002; Haley & Perkins, 2004a). For example, families of children with IDD often reported having a sense of purpose in life, as well as developing new skills and career opportunities from caring for a child with IDD (Hastings & Taunt, 2002); parents of children with various disabilities also reported having positive impact on their lives (Murphy et al., 2007). Similarly, most of the siblings of adults with IDD reported having positive impacts on their sibling relationships with their brother or sister with IDD (Heller & Arnold, 2010). These positive psychosocial outcomes include functioning well, good health, close relationships, low levels of depressive symptoms, and feeling rewarded to care for their brother or sister with IDD. Some negative impacts have also been reported from siblings, such as greater pessimism, more family stress, and greater care demands (Heller & Arnold, 2010). Heller and Arnold (2010) concluded that the impact of having a brother or sister with IDD varies across age groups; studies have found that it might actually raise the risk of negative well-being and poor relationships in childhood, whereas a few studies have indicated that no negative impacts were found among adult siblings of brother or sister with IDD.

Having positive perceptions of the family member with disabilities has been found to be one of the coping strategies which can prevent adverse effects from stresses, as well as protect individuals from traumatic events and thus increase their resiliency in difficult situations (Gupta & Singhal, 2004). Mothers of children with IDD were found to have higher levels of depression than other mothers, whereas some studies indicated that mothers of adults with IDD tended to have normal levels of depression compared to their counterparts (Heller et al., 2007). This phenomenon could be explained by the "adaptation" theory, which believes that aging caregivers are more experienced and become less stressful over time (Caldwell, 2008; Hayden & Heller, 1997; Heller et al., 2007).

Effect of aging among caregivers. The increased life expectancies for both caregivers and their family member with IDD mean that the caregiving experience lasts much longer, and many factors have to be considered in the process. The effect of aging, for instance, is too important to be neglected when discussing caregivers' QoL. It is estimated that around 80% of aging individuals have at least one chronic health condition, and 50% are estimated to have at least two, while the aging caregivers of adults with IDD are not exceptions to these national trends (Yamaki et al., 2009). Caregivers' health have proved to be an important predictor of their levels of QoL (Chou et al., 2011; Greenberg et al., 1993). Bond and Corner (2004) concluded that the most important five elements of the quality of life for aging people are (1) their own health, (2) relationships with family or relatives, (3) finances/standard of living, (4) health of close ones, and (5) social life/leisure activities.

Previous studies have shown that aging mothers can experience stress from other sources, such as their own health issues, changes in their marital status, or takes on caregiving responsibilities for other family members (Chou et al., 2011). Based on Haley and Perkins (2004b), long-term caregiving tasks may increase the risk of having poorer health conditions in the caregivers, due to the physical caregiving demands from the care recipient. For example, osteoarthritis is one of the health conditions that could have a serious impact on the caregiver's capacity to continue providing caregiving duties (Haley & Perkins, 2004b). Aging parents are often worrying about future planning for their adult children with disabilities, as well as other concerns related to learning capacity and physical and mental health (Dillenburger & McKerr, 2010). Some studies have reported that age also influences the stress level and the coping process of the caregivers. For example, Chou, Fu, Lin, and Lee (2011) found that aging female caregivers reported to having less both subjective and objective burdens compare to their younger counterparts. After caring for family member with chronic disabilities for decades, aging caregivers might have already acclimated and adapted to the caregiving demand required at home and been more used to their caregiver roles (Chou et al., 2011), whereas younger caregivers might still be struggling with balancing their life roles. Aging and long-term caregivers may also have narrower everyday life, with declined involvement in employment as well as social life; which means the impact of stigma or guilt does not interfere so much with their daily lives (Chou et al., 2011).

The positive perception of a relative with disabilities has been found to be one of the coping strategies which can prevent adverse effects from stresses, as well as can protect individuals from traumatic events and thus increase their resiliency in difficult situations (Gupta & Sinhal, 2004). Mothers of children with IDD were found to have higher levels of depression than other mothers, whereas some studies indicated that mothers of adults with IDD tended to have normal levels of depression, compared to their counterparts (Heller et al., 2007). This phenomenon can be explained by “adaptation” theory, which believes that aging caregivers are more experienced and become less stressful overtime (Caldwell, 2008; Hayden & Heller, 1997; Heller et al., 2007).

Special Needs of Adults with IDD and Available Resources

The federal government defines developmental disabilities as conditions that pose long-term substantial functional limitations on major life activities, such as self-care, learning, independent living, mobility, and being economically self-sufficient. Although the U.S. disability system has had an emphasis on prioritizing home- and community-based living instead of institutional care (Williamson & Perkins, 2014), community-based living support was only a fraction compared to those who continue to live at home (Yamaki et al., 2009), which could result in greater caregiving demands on the family caregivers. To provide life-long support has become a crucial step for adults with IDD and their aging caregivers, which should include a number of considerations, such as living arrangements, guardianships, and financial consulting, as well as employment (Parish & Lutwick, 2005). However, the service system for people with

IDD is such a complex one to navigate; it is estimated that only 15% of the population has received care from the system (Prouty et al., 2003, cited by Parish & Lutwick, 2005). The complexity of the system also makes it difficult to measure family caregiver outcomes (Williamson & Perkins, 2014).

Williamson and Perkins (2014) listed several available national level resources which support adults with IDD as well as their family caregivers. For example, the 1915 (c) Home and Community-Based Services (HCBS) waiver program was mentioned in their article. It is a system of funding services through Medicaid which allow the provision of long-term care at home or in the community, such as medical services and nonmedical services, (e.g., case management, personal aide, adult daily services, etc.) (Medicaid.gov, n.d.). Since institutions are no longer being considered as the appropriate setting to place people with IDD, smaller community settings, such as supervised group homes or assisted independent living units have become popular options for adults with IDD. In the group homes, the staff usually provides 24/7 supports, including medical support, personal hygiene, and basic housekeeping tasks. Intermediate care facilities for individuals with mental retardation (ICF/MR) provide less around the clock nursing support, compared to the group homes, but ICF/MR has the most individualized comprehensive support, which provides coordinated health care, rehabilitation services, as well as other living skills to individuals with IDD (Lee et al., 2015). The other form of community-based assisted independent living setting is individual supported living (ISL), which is highly individualized with the intention to promote an individual’s life style, well-being, community integration, and participation through various opportunities (Lee et al., 2015). It also provides personal assistance, often offered to meet each individual’s unique needs or situations, including budgeting, shopping, dieting, or personal care tasks (Parish & Lutwick, 2005).

Relationship between Demographics Variables and Caregiver's QoL

Several demographic variables were found to be influential on family caregivers of individuals with IDD. Williamson and Perkins (2014) found that the factors that could influence the mental health status of the caregivers were also identified, such as race/ethnicity, parental role, residence status, and the caregiver's relationship with services and support (Williamson & Perkins, 2014).

Age. Chou et al. (2011) found that compared to younger female caregivers, aging female caregivers had less subjective and less objective burdens. In the same study, the researchers suggested that aging caregivers accommodate themselves to the caregiving demand required at home, and are thus more used to their caregiver roles, whereas younger caregivers still struggle with balancing their life roles.

Race. The race/ethnicity of the caregivers of individuals with dementia were found to have various effects on the caregivers. Black caregivers were more resilient to negative situations than White family caregivers. The negative mental health impact, such as depression and low life satisfactions from providing caregiver tasks, appeared only to occur among White caregivers (Haley et al., 1995). Blacher and McIntyre (2006) also pointed out that Anglo mothers of adults with IDD have lower self-reported depressive symptoms and higher optimism than Latina mothers. However, just how race/ethnicity actually affect the caregiving experiences of family caregivers of adults with IDD is still unknown.

Caregiver role. The present study tends to cover family caregivers, including parents, grandparents, siblings, cousins, or other relatives of adults with IDD. According to a previous study, parental role (mother or father of the individual) was linked to different attitudes toward their children with IDD; specifically, fathers were found to be more pessimistic about the future of their child with IDD, and they used less coping strategies than mothers (Essex et al., 1999a). Since the majority of the past research has been focusing exclusively on parents, it is not so clear if other family caregivers' QoL may or may not be related to providing caregiving tasks to individuals with IDD.

Residential status. Whether or not the caregiver is co-residing with the care recipient, has been found to be correlated to the perceived QoL. Seltzer et al. (2004) found that when aging caregivers co-resided with their adult children with IDD for a long period of time, these caregivers showed significant increases in depressive symptoms and poorer health related QoL, which means that this long term co-residence could have negative impacts on the caregivers' psychological well-being. Krauss et al. (2005) also had a similar finding, which mothers of adults with ASD who continued to live with their adult children reported more negative mental health status than mothers who did not co-reside with their adult children with IDD.

Marital status. Hastings and Taunt (2002) reviewed many past research studies on families' positive perceptions and found that one of the positive impacts raising a child with a disability was "strengthened family and/or marriage" (pp.118). However, Higgin et al. (2005) found that parents or caregivers of children with ASD reported having lower marital satisfaction than did the normed groups. Since it is inconclusive whether having a child with ASD has an impact on marital relationships, how marital status is related to QoL of family caregivers of adults with IDD will be tested in the present study.

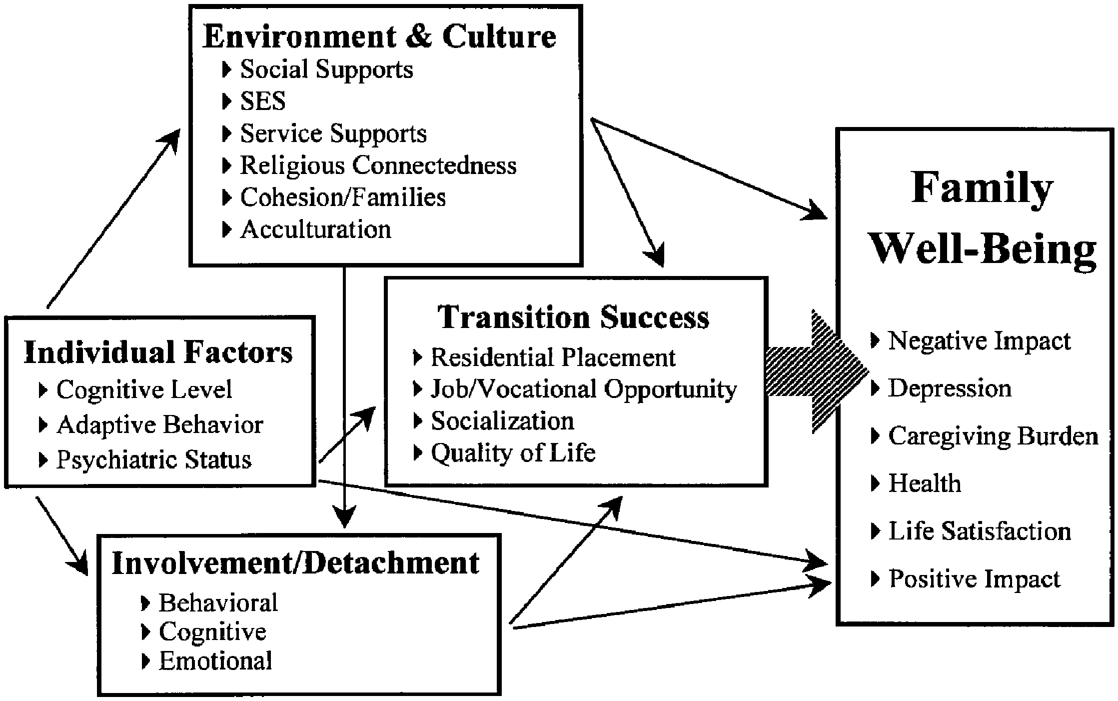
Employment status. Employment relates to QoL. Family caregivers of individuals with IDD tends to have a higher rate of being unemployed or underemployed, which results in financial difficulties and may lead to lower QoL. Luther, Canham, and Cureton (2005) indicated that a family raising a child with a disability may have difficulties maintaining employment, and it may have a hard time finding or paying for adequate childcare. Since adults with IDD tend to continue co-residing with their parents, caregivers may need to postpone or delay employment. With less labor force participation, caregivers may face difficulties in obtaining employment-based coverage in health care (Caldwell, 2008), as well as a lack of stable financial resources, both of which can be additional stressors to the family with individuals with disabilities.

Others. Other demographic variables have been found to be associated with caregiver's overall well-being. Williamson and Perkins (2014) found that family caregiver's mental health relates to the disability type of care recipients with IDD, the caring demands, and the length of caregiving roles.

Examining Existing and Appropriate Conceptual Frameworks

Blacher's Model (2001)

Figure 2: Blacher's Model (2001)

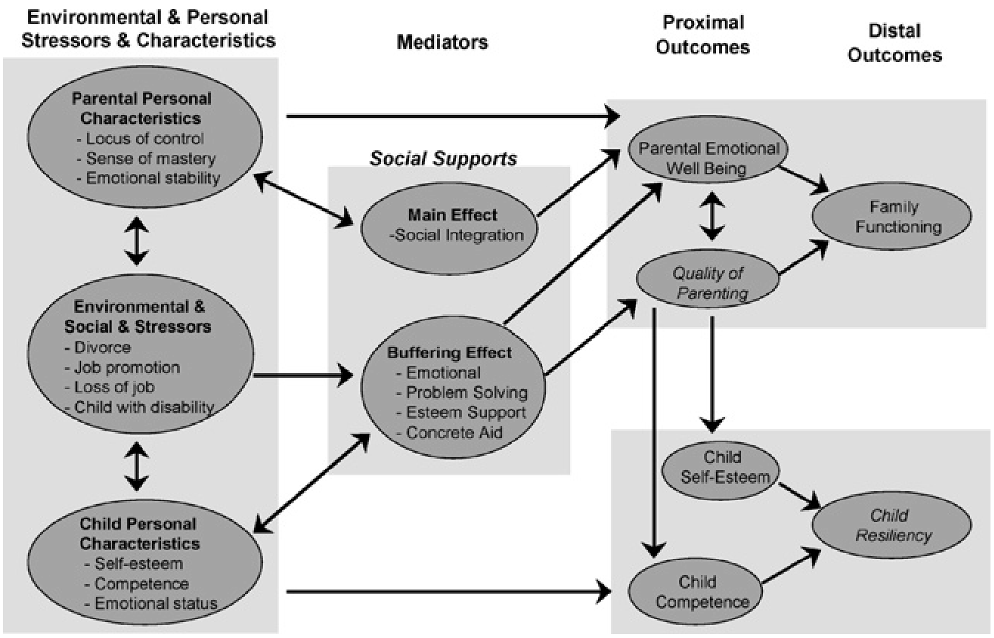


Blacher (2001) proposed a conceptual framework for investigating the transition to adulthood in young adults with intellectual disabilities (ID). In this model, Blacher incorporated the major elements of the well-known ABCX model, such as family outcome, stressors, and family resources, and these major elements were adapted and modified in Blacher's model (Figure 2.1). The primary outcome of Blacher's model is family well-being, which includes elements such as positive and negative impact of transitions on the family. There are other factors that may also influence the transition success included in this model For example, the individual characteristics (cognitive functioning, adaptive behavior, and psychological/emotional status) of the child with ID and family involvement or detachment of the transition services that the child with ID receives could influence both successfulness and family well-being. Resources available for the family, as well as the environmental/cultural factors (socioeconomic status, religious connections, social support, etc.), are also included in this model to predict family well-being.

Since this model focuses on the impact of transition on family well-being, transition related factors are very important ones within this model. For example, residential placement, vocational opportunities, socialization and the QoL of the child with ID are four important desired outcomes of the transition phase. Although residential placement, job opportunities, and socialization cannot be determined as successful or not base on individuals' differences, Blacher (2001) pointed out that QoL can be viewed as a summary of whether the child with ID has a successful transition outcome.

Armstrong, Birnie-Lefcovitch, and Ungar's Model (2005)

Figure 3: Armstrong et al. (2005) Model

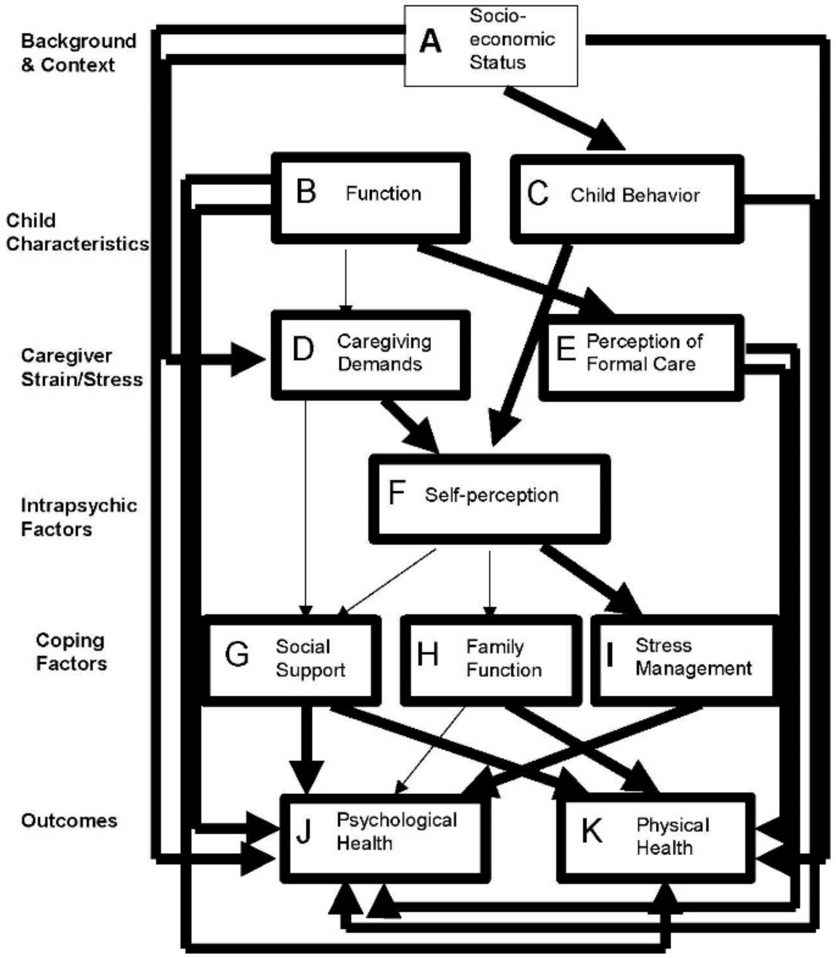


In order to understand the relationships between parental social support, family well-being, parenting capacity, and child resilience among children with serious emotional disturbance, Armstrong, Birnie-Lefcovitch, and Ungar (2005) proposed a conceptual framework to describe the pathways among personal and environmental stressors and characteristics, social supports, family well-being, quality of parenting, and child resilience (see Figure 2.2). The factors included in the model affect family functioning and child resilience, which are distal outcomes of the model. The concept of well-being in this model is similar to the definition of QoL. In fact, Armstrong and colleagues believe that QoL fits within the construct of well-being, and parental emotional well-being is one of the proximal outcomes of the model (the other proximal outcomes are quality of parenting, child self-esteem, and child competence).

In this model, social supports are viewed as mediators between the environmental and personal stressors and characteristics, and between the proximal and distal outcomes. Armstrong and colleagues defined social support as the verbal or non-verbal instrumental, emotional, informational support, such as tangible aid, positive social interaction, affection, and esteem offered by important people, which have beneficial impact on the recipients. The main effects and buffering effects of social support are both included to explain the effects on family well-being.

Raina et al. Model (2004)

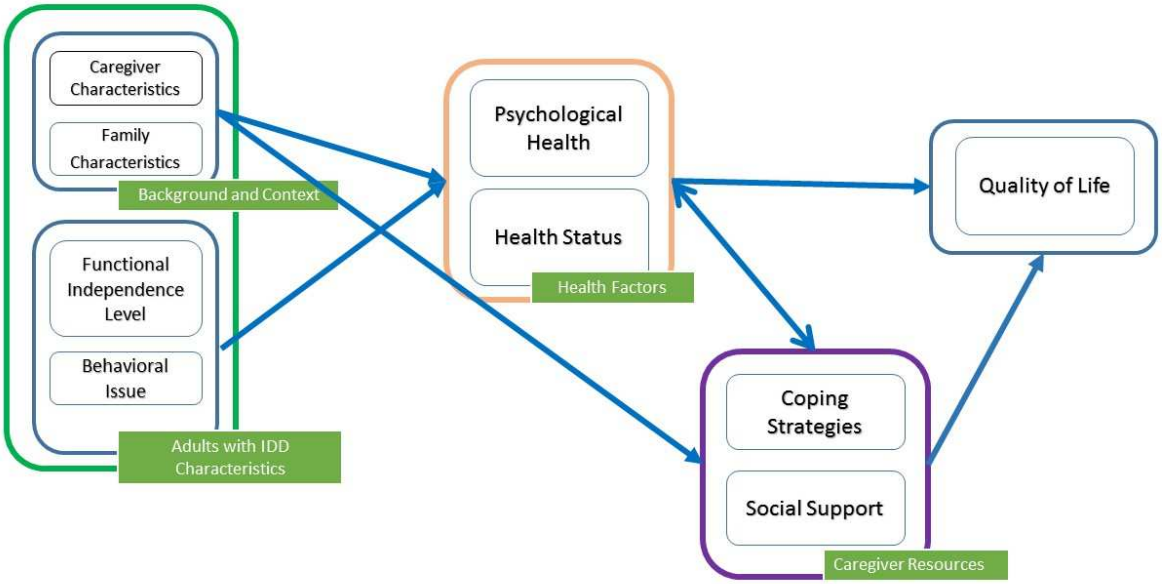
Figure 4: Raina et al. Model (2004)



Raina and colleagues (2004) recognized that multiple dimensions are required in order to better conceptualize the complex direct or indirect pathways between factors during the caregiving process. They developed a comprehensive conceptual model for exploring relationships between the background variables (socioeconomic status, which can be measured by parent's education level, occupation, and family income), child characteristics (severity of disability, as well as levels of functioning), caregiver strain/stress (caregiving demands and perception of formal care), intrapsychic factors (self-esteem, sense of mastery), coping factors (social support, family function, and stress management), and psychological and physical health as the outcomes (see Figure 2.3). The two outcomes that the researchers were interested in are psychological and physical health. They believed that these two outcomes are strongly correlated with the child's conditions, and they are also targets for providing preventions.

Proposed Modified Conceptual Framework

Figure 5: Proposed conceptual framework



To better answer the specific research questions of this present study, the researcher modified and combined the aforementioned three conceptual frameworks (see Figure 2.4). In Blacher's (2001) model, only one type of coping strategy (family involvement with, or detachment from) was included in the model, while in the present study, multiple positive coping strategies (for example, planning and reframing) were included in order to shorten the length of the survey, and the assumption that caregivers would utilize more positive coping skills based on the "adaptation theory. Secondly, the "Transition Success" variable was removed; instead, the present study converted it into one of the characteristics of adults with IDD, "Functional

Independence Level," for which their residential status, employment status, and ADL are being measured. In Armstrong et al.'s (2005) model, three of the proximal outcomes, "Quality of Parenting," "Child Self-esteem," and "Child Competence," and one of the distal outcomes, "Child Resiliency," were not selected to be included in the proposed conceptual model because these factors are not the concerns of the present study.

The present conceptual framework is similar to Raina et al.'s (2004) model because it is the most comprehensive and multidimensional model among the three aforementioned conceptual models. Since the target population of the present study is caregivers of adults with IDD, the functional independence level and the behavioral issue level of adults with IDD were also added to the model. Having a family member with disability is not the only factor affecting the caregiver because overall ageing effects on the caregiver's health condition should also be considered, especially in the target population for the study. Besides, health status was also considered in the context of exploring aging caregivers' QoL. Another stressor is the caregiving demands, which has a lot to do with the type of disabilities, their functional independence level, and the behavioral issue of adults with IDD. For example, children with ASD's maladaptive behaviors have been found to be significantly related to parental stress and coping (Abbeduto et al., 2004; Feldman et al., 2007). Higgins et al. (2005) also pointed out that the severe behavioral problems and ongoing dependency of children with ASD, as well as the limits posed on family activities strongly impact a family's ability to function effectively. The demand of time and energy from caring for people with disabilities is identified as one of the most stressful factors.

Social support and coping strategies are both listed as caregiver resources, because they are both recognized to be predictors of the QoL of caregivers for people with disabilities. The original outcomes of Raina et al.'s (2004) model were physical and psychological well-being. In the present conceptual framework, the researcher believes that physical and psychological well-being are just part of the whole picture. Moreover, it is also noted that past research has tended to focus on related aspects, such as health or psychological well-being rather than the overall QoL (Yoong & Koritsas, 2012). Therefore, these two variables were replaced with one variable: "Quality of Life," in order to consider all the aspects of the caregivers' QoL, such as material well-being, social well-being, and development and activity well-being (Felce & Perry, 1995).

The arrows represent relationships between variables which were identified and evidenced in literature. For example, individuals with IDD's functional independence level and behavioral issues have been found to be associated with caregivers' health status (Abbeduto et al., 2004; Feldman et al., 2007), and social support was found to mediate the relationship between the behavioral problems of children with IDD and caregiver's depressive symptoms (Feldman et al., 2007). Based on these result, the present study is also interested in examining whether coping strategies and social support can mediate the relationships between psychological factors and QoL among caregivers of adults with IDD.

Quality of Life of Caregivers

Although there have been various definitions of QoL, the most widely accepted and recognized definition is from the World Health Organization (WHO). It defines QoL as an individual's perceived level of physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to important features of their environment (Billstedt et al., 2011; Bond & Corner, 2004; Chou et al., 2007; Mugno et al., 2007; World Health Organization, 1996; Yoong & Koritsas, 2012). Shu (2009) indicated that a mother's own feelings were the most prevailing contributing factor to the physical, psychological, and social domains of QoL, and mother's religion was related to the psychological and environmental related domains. Mugno and his colleagues (2007) suggested that socio-economic status, social support, parental and child characteristics, and coping strategies are moderators of QoL within families of children with IDD. Yoong and Koritsas (2012) studied the impacts on the QoL for parents of adults with ID, and found that caring for adults with IDD (1) provides parents with companionship and support; (2) causes negative impacts on the relationships with their spouses; (3) enables parents to develop social support outside of their family member; (4) increases opportunities for engaging in leisure activities; (5) increases personal satisfaction; (6) promotes the positive quality of life; (7) raises financial concerns; and (8) restricts employment opportunities.

Nevertheless, little has been researched regarding the QoL of caregivers of adults with IDD, even though a number of studies have focused on the QoL of caregivers of younger populations with IDD. Given that only limited studies have been conducted on aging caregivers of adults with IDD, one of the purposes of this study is to examine the relationships between contextual factors and QoL among aging caregivers of adults with IDD and how they interact and predict overall QoL of this group of caregivers.

Measurement of QoL. To measure QoL, the most commonly used measurement is the World Health Organization Quality of Life assessment (WHOQOL-100), and the abbreviated WHOQOL-BREF. Several other multi-dimensional measurements are also available, yet since the present study employs the definition from WHO, using the assessment developed by WHO is the most appropriate. WHOQOL-100 is a 100-item assessment, representing 25 facets organized in six domains. In order to avoid respondent burden and to respond to time limits, the WHOQOL-BREF was developed as a short version of the original scale (Skevington et al., 2004). The psychometric properties and more details of WHOQOL-BREF will be discussed in Chapter 3.

Coping Strategies and Caregivers

Lyons, Leon, Phelps, and Dunleavy (2010) indicated that the coping strategies that parents of children with ASD used would affect the likelihood of developing depression. Many researchers have recognized two protective factors which can maintain the resiliency of individuals facing hardship: coping and social support (Lin et al., 2011; Raina et al., 2004; Seltzer et al., 2001). Coping has been defined as problem solving strategies developed by individuals when facing difficulty situations (Schilling, Gilchrist, & Schinke, 1984). For example, Luther, Canham, and Cureton (2005) pointed out that families of children with ASD require strong coping strategies and both formal and informal supports, in order to deal with the intense impact brought to the families by ASD symptoms. Coping is viewed as an important factor in relation to stressful events and adaptation outcomes, such as mental illness as well as physical symptoms (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986), and it is defined by Folkman et al. (1986) as “the person’s constantly changing of cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the person’s resources” (pp. 993). Armstrong (2005) also defined coping as a complicated interaction between the individual and the environment, with the goal of managing the stressor within the environment.

Coping strategies are often divided into two categories in the field of coping studies: problem-focused and emotion-focused coping strategies (e.g., Folkman et al., 1986). Problem-focused coping strategies are strategies focusing on solving problems or making efforts to remove the stressor, whereas emotion-focused coping strategies are ways focusing on reducing or managing negative feelings or distress in response to the stressors (Benson, 2010; Carver & Scheier, 1994). However, Carver, Scheier, and Weintraub (1989) argued that the dichotomous definitions were too narrow, and more variations were needed to explain different coping strategies. Thus, they developed the COPE inventory and identified three dimensions: (1) problem-focused, (2) emotion-focused, and (3) strategies that were viewed as “less useful,” while two subscales, substance use and humor, were added to the full inventory later on (Litman, 2006). Some other researchers have divided coping strategies into three categories: task-oriented, emotion-oriented, and avoidance-oriented (Lyons, Leon, Roecker Phelps, & Dunleavy, 2010; Serrata, 2012). No matter how coping strategies are categorized, they all serve as protective functions in dealing with stressors that come along to provide care to people with disabilities (Serrata, 2012).

From an early study on the caregivers of dementia patients, Haley, Levine, Brown, and Bartolucci (1987) found that coping strategies, especially problem-focused coping strategies, were related to higher levels of life satisfaction, and better health outcomes. Abbeduto et al. (2004) found that mothers of children and adolescents with Down syndrome tended to utilize more problem-focused coping and less emotion-focused coping, which correlated with the effectiveness of buffering the negative impacts of providing caregiving tasks. Additionally, caregivers who used more emotion-focused coping strategies were more likely to have higher levels of psychological stress. Feldman et al. (2007) further confirmed that besides child behavioral issues, escape-avoidance coping strategies and social support both were predictive to a caregiver’s depression level.

Measurement of coping. Some of the common measures to evaluate coping strategies are the Family-Crisis Oriented Personal Evaluation Scale (F-COPE), the Coping Health

Inventory (CHIP), and the COPE Inventory. The F-COPE was developed by McCubbin, Olson, and Larsen in 1987 (Higgins et al., 2005). The F-COPE is a 30-item self-reported survey, which was developed to investigate the problem solving and behavioral strategies used by families when facing crisis situations. The CHIP inventory was developed by McCubbin et al. (1983), to measure the coping strategies used by the primary caregiver of a child with serious or chronic disabilities (Higgins et al., 2005). Because the applied population of this inventory was parents of children with chronic disabilities, even though it was a widely used inventory, it was not chosen by the present study. The other most frequently used measurement for the study of caregiver's coping strategies is the COPE inventory (Carver, Scheier, & Weintraub et al., 1989). It is a multi-dimensional inventory to assess how people respond to stressful situations which will be used in this study. More details about this inventory will be explained in Chapter 3.

Social Support and Caregivers

Social support is one of the protective factors for family caregivers (Heller et al., 2007). Some researchers consider social support as one type of coping mechanisms (e.g., Dunn, Burnie, Bowers, & Tantleff-Dunn, 2001; Thoits, 1995) which has been found to serve as a buffer factor against stress. It is defined as individuals or groups (e.g., family members, friends) who provide various degrees of instrumental, informational, and/or emotional resources or assistance to help individuals overcome the hurdles (Schilling, Gilchrist, & Schinke, 1984; Thoits, 1995). It is also a very valuable resource for providing both tangible or intangible forms of help that individuals receive from their family or friends; furthermore, social support can protect people from the pathogenic effects of stress (Clipp & George, 1990; Cohen, Mermelstein, Kamarck, & Hoberman, 1985). Twoy et al. (2007) indicated that it is crucial to have active coping strategies and support from others at the same time, rather than just using avoidance coping strategies to deal with the difficulties. Caregivers can express their anxious feelings regarding caring for individuals with IDD through their social support networks (Serrata, 2012). Many perspectives as mentioned above can define social support. The present study uses the definition from Schilling et al. (1984) because it fits well with the research questions of the present study, and it explicitly explain the origins and functions of social support.

Studies have shown that more accessible social support that mothers have, greater family cohesion, and more active coping strategies lead to lower caregiving burdens, less stress-related health issues, and fewer depressive symptom (Dunn et al., 2001; Heller et al., 2007). Similarly, Ben-Zur et al. (2005) studied mothers of adults with ID and found that regardless of the residential status of their adult children, social support was strongly related to mothers' mental health status. Furthermore, Feldman et al. (2007) also noted that social support mediated the relationship between the child with ASD's behavioral issues and the caregiver's depressive symptoms. Satisfaction with one's social support networks and the level of available informal social support are both related to lower depression level, more positive caregiving attitudes, better physical health, and better personal well-being (Raina et al., 2004).

Weinert (2003) and Seltzer, Greenberg, Floyd, and Hong (2004) indicated that coping and social support are protective factors that can buffer the negative impacts from caring for adult children with IDD or mental health problems. Similarly, Raina et al., (2004) identified that among parents of children with disabilities, social support is related to higher maternal psychological adjustment; it can mediate the well-being of parents and the relationship between stressors and outcomes and also predict family adjustment, which is associated with mental health and social functioning. Other researchers have also confirmed that coping strategies and degree of social support are predictive factors of caregivers' well-being, and may buffer the effects of stressors on family adaptation (Lin et al., 2011). Numerous studies have confirmed that social support plays a role in buffering the negative impacts from the caregiving burden. For example, Abbeduto et al. (2004) pointed out that the predictability of children with disabilities' maladaptive behaviors is an important predictor of stress and coping of the parents.

When examining the effects that coping strategies and social support have on caregivers, researchers have often found mediation and/or moderation effects. For example, from an early study by Haley et al. (1987), the researchers found that social support, appraisals, and coping responses have mediating effects on individuals' differences in depression, health, and life satisfaction. However, more recently, Feldman et al. (2007) found that social support was the only variable that mediates the relationship between a caregiver's level of depression and a child's behavioral issues.

Measures for social support. Clipp and George (1990) suggested that a multi-dimensional perspective on social support should be used to understand fully how social support contributes to the quality of life. However, as Cohen and colleagues (1985) suggested, there are too many measurements available to assess social support, and considerations should be included to choose one appropriate measurement for the research questions of a study. Some commonly used measurements for social support include Family Support Scales, which measures the availability and the helpfulness of both formal (professional support) and informal supports (friends and families)(White & Hastings, 2004); and the Duke Social Support Index (DSSI), which was developed by Landerman and colleagues (1989) to measure the social network of the elderly and the support provided by that network. Four dimensions were assessed in DSSI: satisfaction with social support, perceived social support, frequency of social interaction, and the size of the network (Landerman, George, Campbell, & Blazer, 1989). Besides, Personal

Resource Questionnaire (PRQ-2000; Weinert, 2003) is another common measure which is a 15-item questionnaire to identify the perceived level of social support as a nursing measurement. In addition, the Interpersonal Support Evaluation List (ISEL; Cohen et al. 1985) will be used in the present study because the operational definition of social support is “the resources that are provided by other persons” (pp.73), which is very similar to Schilling et al. (1984)’s definition and the definition applied in the present study. When developing this scale, Cohen and his colleagues (1985) categorized four different support functions: tangible support, appraisal support, self-esteem support, and belonging support. Also, the relevance to the hypothesis and population of interest of the current study of the ISEL are important to use this scale to assess the perceived informal social support among family caregivers of adults with IDD. More details will be discussed in the Instruments section in Chapter 3.

CHAPTER 3

METHODS

This chapter presents the research design and methods of the study, organized in five sections. First, the research design will be explained; secondly, information of sample and participant's selection will be provided; thirdly and fourthly, the procedures of carrying out the present study in order to answer the research questions will be presented, followed by instruments' description. The fifth section presents the data analysis procedures.

Research Design

A cross-sectional descriptive correlational design was used in the present study to examine the relationships between variables, such as relationship between demographic variables in perceived social support, coping strategies, and overall QoL. Additionally, the mediation effects of caregivers' health status (i.e., depressive symptoms and perceived stress level) on QoL among aging family caregivers of adults with IDD was examined. The study was designed to use a quantitative methods approach, with a number of psychosocial measures. Quantitative methods allow researchers to have broad, generalizable findings by collecting a large number of responses from different states in the nation.

Sample and Participants Selection

The target population for this study was family caregivers for adults with IDD. The inclusion criteria of this study were: 1) potential participants must be family members who are currently taking care of adults (age 18 or above) with intellectual and/or developmental disabilities (IDD); 2) who identify themselves as primary caregivers for the past one month; and 3) who provide care for at least 10 hours per week. To ensure inclusion of participants with a variety of backgrounds, participants were recruited via different agencies (both public and private), social media support groups (Facebook), resource fairs, and through mailing lists from various states across United States. All of the potential agencies were identified because they were listed as resources on each state or county's official webpage for individuals with IDD and their families. A purposive sample of 266 family caregivers for adults with IDD attempted the online and hard copy survey between September 2015 and March 2016. Of those surveys, 184 (70%) participants provided incomplete or invalid data. The final study sample included 82 (31%) participants. One participant completed the hard copy survey and 81 participants used online survey.

Family caregivers were mostly female (89%) and White (87%). The majority of the family caregivers for adults with IDD were parents (91%), the rest were other caregivers such as siblings, spouse, and relatives. The ages of the family caregivers range from 30 to 79, with a mean of 53.41 (*SD*=9.23). Almost half of the sample were in the 50-59 age group (48%). As for the marital status, 76% of the caregivers were married. Most of the caregivers worked for full time (48%), 28% of caregivers had part-time work, and 24% of participants were not employed or were retired. The caregivers participated in this study were quite educated; majority of them had at least an associate degree (88%) with 53% had a Bachelor's degree or higher. Most of the caregivers (42%) had over $70,000 in annual household income which was higher than the median household income in the United States ($53,657; US Census Bureau, 2015).

Procedure

Following approval by the IRB at MSU, the researcher contacted local community-based agencies, vocational services agencies, support groups, and various listserv, which provide services to adults with IDD. Official invitation letters, including information about the study (such as IRB approval notice, consent forms, and questionnaire), were sent via email to identified agencies, to request research collaboration. Upon agreement, those participating organizations disseminated flyer and information about the research project to their members/clients, to recruit them as participants. Interested participants then used the direct link including in the flyer to participate the survey via online survey platform (Qualtrics), or mailed back the paper version questionnaire to the researcher. More than 2,200 email invitations were sent out to various agencies and personnel who worked with people with IDD and the families. Agencies who were willing to help with the recruitment process then posted the study message on their websites or through listserv. A total of 266 entries (265 online responses and 1 paper questionnaire) were received between September 2015 and March 2016, with 82 usable responses could be retained in the final sample. Entries with incomplete or invalid responses were removed from the dataset.

The average time for completing the entire set of questionnaires was approximately 15-30 minutes. Participants were informed that the researcher was available through telephone and email to answer questions. Due to the length of this questionnaire, all participants were provided with opportunities to leave their contact information to receive a $10 gift card.

Instrumentation

The survey includes several different instruments that represent different parts of the conceptual framework and QoL as the outcome of interest: (1) demographic information; (2) functional independence level; (3) behavioral issues; (3) psychological factors; (4) social support (5) coping strategies; and (6) quality of life. Table 3.1 provides a brief summary of all the instruments to be used in this study.

The dependent variable (DV) investigated in this study was the overall perceived quality of life, physical and psychological related QoL among family caregivers of adults with IDD. The

17 independent variables (IV) included are categorized into four sets, which include: caregiver's characteristic (8 variables: age, gender, race/ethnicity, education level, annual household income, marital status, employment status, caregiver role, and residence status); adults with IDD's characteristic (5 variables: age, types of disabilities, functional limitation, behavioral issues, and employment/education status); caregiver health status (2 variables: depression, perceived stress); caregiver resources (2 variables: coping strategies and social support).

Participants' demographic information was asked first to capture the participants' general characteristics which include both caregiver and care recipient's information. Caregiver related characteristics were age, race/ethnicity, gender, marital status, caregiver role, annual household income, education level, and employment status; care recipients related characteristics were age, functional level, behavioral issues, residential status, employment status, and SSA beneficiary.

Table 3. 1
List of instruments

Variables	**# of Items**	**Instrument**
Demographic Information	21 items	Demographic Questionnaire
Functional Independence Level	17 items	Waisman Activities of Daily Living Scale (W-ADL)
Behavioral Issues	9 items	Extracted from: Assessment for Adults with Developmental Disabilities (AADS)
Psychological Factor	9 items 14 items	Patient Health Questionnaire (PHQ-9) Perceived Stress Scale (PSS)
Coping strategies	16 items	Extracted from: BRIEF-COPE
Social Support	12 items	Interpersonal Support Evaluation List-12 (ISEL-12)
Quality of Life	26 items	WHOQOL-BREF
Total number of items	124 items	

The following is a description of each instrument, including the name of the instrument, definitions and sample questions, and psychometric properties where applicable.

Demographic Information

Based on the literature review, the demographic variables that were collected in the present study include age, race/ethnicity, gender, and education level, household income, marital status, employment status, health conditions, and roles/relationships with the care recipient (e.g., parents, siblings, or other relatives). These demographic variables were chosen because of their roles in predicting the QoL based on previous research. Employment status and the annual household income may have impact on material well-being, whereas physical well-being may be affected by age and gender. Demographic information of the care recipients with IDD was collected in the following areas: age, diagnosis, residential status (e.g., reside with family, independent living, or group home), employment status (full time, part time, volunteer, or still in school), SSA beneficiary (e.g., SSI and/or SSDI, Medicaid and/or Medicare).

Functional and Independence Level

Care recipient's functional independence level was assessed through the Waisman Activities of Daily Living Scale (W-ADL; Maenner et al., 2013). The W-ADL scale was developed by Maenner et al. (2013) specifically for adolescents and adults with IDD, to assess their activity limitations systematically and it has been approved to have acceptable psychometric properties. The W-ADL's target population fits well with the present study. It is a 3-point Likert scale (2= independent or does on own; 1= does with help; 0= does not do at all), with the higher the score indicates the higher the individual's functional independence level is. The internal consistency for this measure in the present study was found to be good (Cronbach's α=.95). Table 3.2 presents examples of the scale.

Table 3. 2
Sample questions from the WADL

Rate Participant's Level of independence in…	**Ability to Perform Task** 2= independent or does on own 1= does with help 0= does not do at all		
Q1. Making his/her own bed	0	1	2
Q10. Preparing simple foods requiring no mixing or cooking, including sandwiches, cold cereals, etc.	0	1	2
Q17. Banking and managing daily finances, including keeping track of cash, checking account, paying bills, etc. (Note: if he/she can do a portion but not all circle '1' with help.)	0	1	2

Behavioral Issues

Assessment for Adults with Developmental Disabilities (AADS). To assess an individual's behavioral issues, the *Assessment for Adults with Developmental Disabilities* (AADS) will be used. The AADS scale was developed by Kalsy, McQuillan, Oliver, Hall, and Oyebode (2001) for adults with developmental/learning disabilities, to evaluate dementia-related behaviors that may be experienced by individuals with developmental/learning disabilities as they get older. This scale is an informant-based questionnaire with two subscales: behavioral excess (11 items), and behavioral deficits (17 items) which are commonly associated with dementia (Kalsy, McQuillan, Oliver, Hall, & Oyebode, 2001).

However, since the present study is only interested in the behavioral issues of individuals with IDD, some of original AADS dementia-related items are not appropriate for this study. Thus, nine items which represent behavioral issues were selected to be used as abbreviated

AADS in the current study for caregivers to rate the care recipients' behavioral issues, and the caregivers rated on a 7-point Likert scale in terms of the frequency (from 0="has not occurred in the past two weeks" to 6="once an hour/all of the time") and the management difficulty (from 0="no difficulty" to 6="extremely severe difficulty"). For the sample of this study, the Cronbach's alpha is .94 which is considered to be good. Table 3.3 shows sample questions from the abbreviated AADS.

Table 3. 3
Sample questions from the AADS

	How often	Management difficulty
Q1. Was Restless. Paced up and down, was unable to sit still, fidgeted.	0 1 2 3 4 5 6	0 1 2 3 4 5 6
Q8. Was aggressive toward others verbally or through gestures. Expressed aggression towards others or by using signs/gestures (e.g. shouted, name called, threatened, or swore).	0 1 2 3 4 5 6	0 1 2 3 4 5 6
Q10. Displayed sexually inappropriately behavior. Made an inappropriate sexual advance/gesture, made sexual references, non-accidentally exposed self	0 1 2 3 4 5 6	0 1 2 3 4 5 6

Psychological Factors

Two measures were chosen to examine the psychological factors among aging caregivers of adults with IDD.

Patient Health Questionnaire (PHQ-9). The first one is the Patient Health Questionnaire (PHQ-9), developed by Spitzer, Williams, and Kroenke and colleagues (Kroenke, Spitzer, & Williams, 2001). PHQ-9which is a depression screening tool and incorporates DSM-IV depression diagnostic criteria and other major depressive symptoms into the questionnaire. It contains nine items (which represent depressive symptom criteria) and can be filled out in a very short amount of time. The respondents answer each question to reflect how often they have been bothered by certain scenarios over the last two weeks on a 4-point Likert scale (from 0="not at all" to 3="nearly every day"), providing a 0=27 total severity score. At the end of the nine questions, the questionnaire also asks the participants to rate how difficult it has been to be able to maintain their normal life, such as working, doing chores, or interacting with others. This 10th question serves the purpose of weighing how severe it is that the depressive symptoms have impact on the client's function level. In the present study, this question was used to provide additional information on the respondent, not for the scoring purpose. The higher the score indicates the more severe the respondent's depressive symptoms might be.

The psychometrics properties of the PHQ-9 were examined often among different populations. The internal consistency reliability (Cronbach's alpha) ranges from .79 to .90; and the test-rest reliability ranges from .76 to .96 (Rehab Measures - Patient Health Questionnaire (PHQ-9), 2013), which indicates that PHQ-9 is a valid and reliable measure (Rehab Measures - Patient Health Questionnaire (PHQ-9), 2013). For the sample of the present study, it was also found to have good internal consistency (Cronbach's α=.89). Table 4 shows three sample questions from the PHQ-9.

Table 3. 4
Sample questions from the PHQ-9

	Not at all	Several days	More than half of the days	Nearly every day

Table 3.4 (cont'd)

Q1. Little interest or pleasure in doing things	0	1	2	3
Q2. Feeling down, depressed, or hopeless.	0	1	2	3
Q3. Trouble falling or staying asleep, or sleeping too much,	0	1	2	3

Perceived Stress Scale (PSS). The second measure, Perceived Stress Scale (PSS) developed by Cohen and his team (1983), is a self-administered questionnaire with only 14 items, with seven positive items and seven negative items, was used to measure family caregivers' perceived stress. PSS is widely used in the psychology field to measure which events in one's life are perceived as stressful (Cohen, Kamarck, & Mermelstein, 1983). The scale was designed to explore how unpredictable, uncontrollable, and overloaded respondents find their lives (Cohen & Williamson, 1988). The questionnaire asks respondents to rate the frequency of their feelings and thoughts during the last month on a five-point Likert scale (from 0="never" to 4="often") with higher scores suggesting the individual has a higher level of chronic stress. Table 3.5 lists a few sample questions from the PSS.

The psychometric properties of the PSS were examined across various studies. Lee (2012) reviewed all of the studies and concluded that the PSS has had good psychometric properties across different studies. Both the internal consistency reliability (Cronbach's alpha) and the test-retest reliability were above .70. In the present study, it was found that PSS had a questionable internal consistency for the sample of the study (Cronbach's α=.58). The exploratory factor analysis for the PSS-14 indicated that a two-factor structure was more dominant than a one-factor structure; however, in some studies, the two-factor structure only accounted for less than 50% of the variance. PSS-14 was also found to be highly correlated with the mental component of SF-36.

Table 3. 5
Sample questions from the PSS

	Never	Almost never	Sometimes	Fairly often	Very often
Q1. In the last month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
Q3. In the last month, how often have you felt nervous and “stressed”?	0	1	2	3	4
Q7. In the last month, how often have you felt that things were going your way?	0	1	2	3	4

Coping Strategies

Brief COPE Inventory. The Brief COPE inventory was used to examine the family caregiver’s coping strategies in difficult situations, and also to compare the use of different coping strategies among different groups of family caregivers in the present study. The original COPE inventory was developed by Carver, Scheier, and Weintraub (1989), to assess the different ways people respond to stressful situations. Carver et al. (1989) identified three dimensions: (1) problem-focused (five subscales), (2) emotion-focused (five subscales), and (3) strategies that were viewed as “less useful” (three subscales). Two subscales, substance use and humor, were added to the full inventory later on (Litman, 2006). Due to the length and the redundancy of the full version (60 questions), Carver (1997) then reduced the full version to a brief scale, which only had 28 questions. A total of 14 subscales were included in the Brief COPE inventory; 13

subscales were the same subscales from the full version of COPE, and one new subscale, self-blame, was added to the inventory. It employs a 4-point Likert scale (from 1="I haven't been doing this at all" to 4= "I've been doing this a lot").

Just like the full version of the COPE Inventory, the Brief COPE has been found to have acceptable psychometric properties, such as internal consistency (Cronbach's alpha) ranged from .50-.90 of each abbreviated subscales. Despite the fact that each subscale only has 2 items, the reliabilities all meet the minimum requirement of .50 (Carver, 1997). For the purpose of this study, only eight positive coping skills (16 questions) were chosen to be included in the questionnaire. For the sample of the present study, it was also found to have good internal consistency (Cronbach's α=.88). Table 3.6 lists the eight subscale chosen for the present study and the sample questions for each scale.

Table 3. 6

Domains and sample questions from the Brief COPE

Domain	**Sample Question**
Active coping	Q2: I've been concentrating my efforts on doing something about the situation I'm in.
Use of emotional support	Q5: I've been getting emotional support from others.
Use of instrumental support	Q10: I've been getting help and advice from other people.
Positive reframing	Q12: I've been trying to see it in a different light, to make it seem more positive.
Planning	Q14: I've been trying to come up with a strategy about what to do.
Humor	Q18: I've been making jokes about it.
Acceptance	Q20: I've been accepting the reality of the fact that it has happened.
Religion	Q22: I've been trying to find comfort in my religion or spiritual beliefs.

Social Support

Interpersonal Support Evaluation List (ISEL). The Interpersonal Support Evaluation List (ISEL) was developed by Cohen and his colleagues (Cohen, Mermelstein, Kamarck, & Hoberman, 1985), and the abbreviated scale was chosen to measure perceptions of social support among aging caregivers in the present study. The original ISEL has 40 items, which represent four domains: (1) tangible support, (2) appraisal support, (3) self-esteem, and (4) belonging. The abbreviated ISEL has 12 items, which are based on three domains: (1) appraisal support, (2) belonging support, and (3) tangible support. Each subscale has four items with each rated by the participants on a 4-point Likert scale (1="definitely false" to 4="definitely true") with higher scores reflecting greater perceived availability of support resources by the respondents; and these items are divided into three different subscales to measure the perceived social support.

The abbreviated ISEL has been proved to possess adequate test-retest and internal consistency reliability, just as the original scale did. Internal consistency reliability (Cronbach's Alpha) of general population ranged from .81 to .91; the two-day interval test-rest reliability was .87, and the six-month interval test-retest reliability was .77. The ISEL-12 subscales also have been tested, and they have been proven to have moderate degree of correlations with ISEL-12 and each subscales of SF-36 between .30 and .41 (Cohen, 2008). In the present study, it was found that ISEL-12 had good internal consistency, with a Cronbach's α=.89. Table 3.7 describes each of the domains of ISEL and the sample questions.

Table 3. 7
Domains and sample questions from the ISEL

Domain	Sample Questions
Appraisal Support	Q2: I feel that there is no one I can share my most private worries and fears with.

Table 3.7 (cont'd)

Belonging Support	Q7: I don't often get invited to do things with others.
Tangible Support	Q8: If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc.).

Quality of Life

World Health Organization Quality of Life-Brief version (WHOQOL-BREF). The World Health Organization Quality of Life- Brief version (WHOQOL-BREF) was used to assess participants' perceived quality of life. It is a well-known QoL measure that was developed by the WHO and has been utilized throughout the world. The original WHOQOL had 100 items, and it was developed to be cross-culturally appropriate; it then was shortened to a total of 26 questions to avoid the lengthy time demands of the WHOQOL-100. The respondents rate how he/she felt his/her QoL was during the past two weeks on a five-point Likert scale (1="Very dissatisfied/very poor/not at all/never" to 5="Very satisfied/good/completely/always"). The WHOQOL-BREF is scored on four domains: (1) physical health—daily activity, mobility, and work capacity; (2) psychological—negative and positive feelings, and self-esteem; (3) social relationships—personal relationship, social support, and sexual relationship; and (4) environment—financial resources, physical environment, and transportation. The four domain scores denote an individual's perception of their own QoL in each particular domain, with higher score denoting higher QoL. And for the purpose of this study, the main focus was on physical related QoL, psychological related QoL, and the overall QoL.

There are two steps for transforming the raw scores into the final scale score; the first step converts raw scores to a range between 4 and 20, and the second step converts the domain scores to a scale from 0 to 100. There are 24 items focusing on these four domains as well as 2 items focusing on the general health and overall QoL. Table 3.8 contains facets that are incorporated within domains and a sample question for each domain.

This assessment has acceptable psychometric properties. The Cronbach's alpha was found acceptable for the three domains, indicating the scale has internal consistency. By comparing sick and well respondents, it showed that discriminant validity was significant for each domain. Factor analysis of the total population data showed four factors (eigenvalues >1.0) that explained 53% of the variance in the data. The psychological and social domains showed significant gender differences, indicating that women had better social QoL, but poorer psychological QoL, than men. Also, mean domain scores decreased with age, and the greatest changes were to be found in physical health (Skevington et al., 2004). From the samples of the present study, WHOQOL-BREF was found to have good internal consistencies for both physical related domain (Cronbach's α=.80), and psychological related domain (Cronbach's α=.87).

Table 3. 8
Domains, Facets, and Sample Questions from the WHOQOL-BREF

Domain	Facets Incorporated	Sample Questions
Physical health	Activities of daily living; dependence on medicinal substances and medical aids; energy and fatigue; mobility; pain and discomfort; sleep and rest; work capacity	Q10: Do you have enough energy for everyday life?
Psychological	Bodily image and appearance; negative feelings; positive feelings; self-esteem; spirituality/religion/personal beliefs; thinking, learning, memory, and concentration	Q19: How satisfied are you with yourself?

Table 3.8 (cont'd)

Social Relationships	Personal relationships; social support; sexual activity	Q22: How satisfied are you with the support you get from your friends?
Environment	Financial resources; freedom, physical safety and security; health and social care: accessibility and quality; home environment; opportunities for acquiring new information and skills; participation in and opportunities for recreation/leisure activities; physical environment (pollution/noise/traffic/climate); transport	Q8: How safe do you feel in your daily life

Data Analysis

Descriptive Statistics Analyses

Descriptive statistics was used to present the demographic characteristics of the participants, such as gender, age, educational level, and annual household income. Means, ranges, and standard deviations was presented for the continuous variables, and frequencies and percentages was presented for the categorical variables.

Correlation Analyses

To answer research question #1, two different correlational tests were used to examine the relationship between key independent variables (IVs) and dependent variables (DVs), based on specific types of variables. Specifically, Spearman correlation tests were conducted to examine the relationships between ordinal variables (e.g., education level, annual household income) and QoL. Pearson correlation tests were used to evaluate the associations between continuous variables (e.g., age, scores of measures) and QoL. In addition, analysis of variance

(ANOVA) was conducted to assess group differences with respect to various demographics variables. Based on previous study results, some examples of group differences were caregiver role (parents or others) and residency status (co-reside with the individual with IDD or not). All statistical tests were carried out at the significance level of .05. For multiple analyses, Bonferroni correction was used to control Type I error.

Hierarchical Regression Analyses

Hierarchical regression analysis is commonly used to predict a DV using a set of IVs step by step, based on theoretically driven decisions for the sequence of entering predictors into the analysis (Petrocelli, 2003). To answer research question #2, three sets of IVs were entered into the regression model to predict the outcome variable (i.e., QoL). Specifically, hierarchical regression analysis was employed in this study to validate the conceptual framework as a comprehensive model for understanding how different contextual factors affect QoL of family caregivers of adults with IDD by examining the relationships between the different constructs and different aspects of QoL. Each of the three sets of IVs which belong to the same construct were entered in an order base on the theoretical expectations of the framework and preliminary correlational tests, and then assessed in terms of what it adds to the equation at its own point of entry. The significance was set at alpha = .05. The hierarchical regression model includes the following a priori specifications.

> **Step 1.** A set of four demographic covariates were entered into the model, which includes background information regarding both the aging caregivers and the care recipient (i.e., adults with IDD). Specifically, demographic variables of the caregivers include age; demographic variables of the care recipient were age, functional independence level, and

behavioral issue level. This step was to examine the effect of the demographic variables on the QoL among family caregivers.

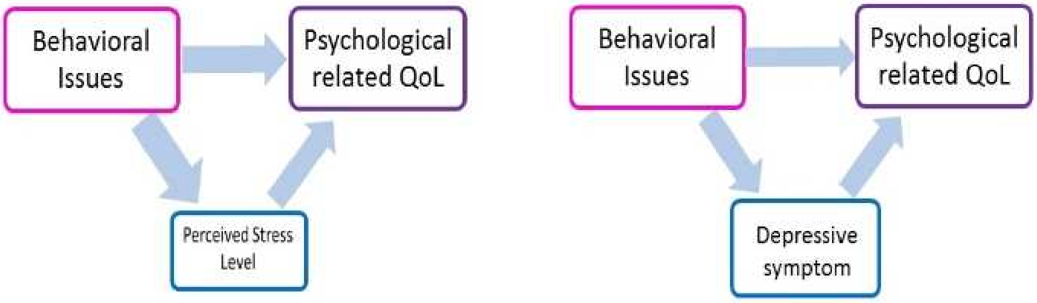
Step 2. The five variables to be entered into the analysis were aging caregiver's health status, which includes both psychological (depression, perceived stress), whether or not the caregivers had health conditions (only for physical and psychological related QoL), and co-residency (only for psychological related QoL). In this step, the relationships between the aging caregiver's health status and QoL were determined, after controlling for the effects of both the caregivers' and the care recipients' demographic covariates.

Step 3. In this step, two variables of caregivers' resources were entered into the model. These variables include aging caregivers' coping strategies and social support. The effects of both coping strategies and social support on the overall QoL were determined after controlling for the effects of demographic covariates and psychological and overall health status.

Mediation Analysis

Mediation analyses are often used in educational and psychological studies. The method studies how IVs influence the DV quantifies the mechanism which causes the effects between the variables (Hayes & Preacher, 2014). A mediator analysis hypothesizes that the outcome variable is mediated by various variables in the process, and these variables account for the relation between the predictor and the criterion variable (Baron & Kenny, 1986). Baron and Kenny (1986) also indicated that mediators explain how or why the interactions occur when certain effects take place. Mediation analyses was used to study the interweaving relationships between the variables. Specifically in this study, two single mediation analyses were conducted to answer research question #3, to determine whether the caregivers' psychological factors (depressive symptoms and perceived stress level) mediate the relationship between behavioral issues of adults with IDD and the psychological related QoL among family caregivers.

Figure 6: Mediator Model



CHAPTER 4

RESULTS

The purpose of this study is to use various surveys to examine the perceived quality of life (QoL) of family caregivers of adults with IDD under a proposed theoretical framework. The results provide a basis to better understand how family caregivers perceived their QoL while providing care to their adult family members with IDD. This chapter starts by explaining data entry process, missing data handling, followed by demographic information of the participants, results of correlational analyses, hierarchical regression analyses, and mediation analyses.

Missing Data Handling

Survey dataset were downloaded directly from the electronic survey platform (Qualtrics.com) and imported into SPSS after cleaning for the unneeded data. All analyses were conducted using the Statistical Package for the Social Science 23 for Windows (SPSS; IBM, 2015).

Multiple imputation (MI) procedures were used to treat the missing data for this study so that the sample size could be maintained. MI runs simulation on the missing data relative to the current dataset, and replace the missing data with the most likely data depending on the trend of the existing data. First, the pattern was analyzed to determine if the missing data could be trimmed or not. Based on the pattern analysis, the missing data was determined to be "missing at random". There were 17 out of 82 participants (20.73%) of participants missed certain responses in various survey items. The multiple imputation was carried out to replace those missing responses.

It is recommended to set a random seed prior to conduct MI to allow future replication of the study (Meyer, Gamst, & Guarino, 2012). MI was therefore performed after setting the random seed procedure. Automatic imputation was conducted with five imputations. According to the results of the imputation model, SPSS chose monotone imputation method, and the variables area listed in their imputation sequence order, which is Psychological Related QoL, Physical Related QoL, Social Support Related QoL, and Environmental Related QoL.

Demographic Information

Family Caregivers’ Demographic Characteristics (See Table 4.1)

The caregivers had a variety of caregiving experience, ranging from six months to 55 years. About half of the caregivers who participated in this study have been primary caregivers for adults with IDD for more than 20 years, with a little bit less than half of the caregivers have been primary caregivers for less than 20 years. As for the average hours per week, 34 caregivers reported to provide more than 100 hours per week, with 26 caregivers reported to provide more than 40 hours care to the adults with IDD every week. Specifically, among those who provided more than 100 hours a week, there were 11 caregivers reported that they had to provide 24/7 or daily care to adults with IDD, except when adults with IDD were in school or in day program. A quarter of the caregivers (24.4%) reported currently using respite care services, whereas 19.5% had use respite care services only in the past. However, 14.6% reported that respite care services were not available for their families (see Table 4.1).

Table 4. 1

Family caregiver's characteristics

Variable		*N*	*%*
Gender			
	Female	73	89.0%
	Male	9	11.0%
Age			
	30-49	24	29.3%
	50-59	39	47.6%
	60 and older	19	23.2%
Race/Ethnicity			
	White	71	86.6%
	Non-White	11	13.4%
Marital Status			
	Married	62	75.6%
	Not married (single, divorced, or widowed)	20	24.4%
Employment Status			
	Full time	39	47.6%
	Part time	23	28.1%
	Others (not employed or retired)	20	24.4%
Education Level			
	High school or below	6	7.4%
	Associates	29	35.6%
	Bachelors	22	26.8%
	Some graduate or higher	21	25.6%
	Other	2	2.5%
Annual Household Income			
	Below 40K	20	24.39%
	40-70K	22	26.9%
	70K and above	34	41.5%
	Prefer not to answer	6	7.3%
Years of Being Caregiver			
	0-10 years	10	12.2%
	11-20 years	26	31.7%
	21-30 years	31	37.8%
	Over 30 years	16	19.51%

Table 4.1 (cont'd)

Variable		***N***	***%***
Avg. Caregiving Hours (per week)	10-35 hours	22	26.83%
	35-100 hours	26	31.7%
	100+ hours	34	41.46%
Residence Status	Co-reside with adults with IDD	75	91.5%
	Not co-reside with adults with IDD	7	8.5%
Utilization of Respite Care	Yes	20	24.4%
	Only in the past	16	19.5%
	Considering	18	22.0%
	No need	16	19.5%
	Not available	12	14.6%
Comorbid Health Conditions	Yes	38	46.3%
	No	40	48.8%
	Prefer not to answer	4	4.9%
Duration of the Condition(s)	2~5 years	9	23.7%
	Over 5 years	29	76.3%
Types of Health Condition(s)	High blood pressure	15	38.5%
	Back pain	12	30.8%
	Depression	12	30.8%
	Arthritis	11	28.2%
	Hearing impairment	9	23.1%
	Obesity	9	23.1%
	Anxiety	8	20.5%
	Others	14	35.9%

Caregiver Health Status

Approximately half (46.34%) of participants reported to have at least one health condition with the mostly reported four symptoms being: high blood pressure (38.2%), back pain (30.8%), depression (30.8%), and arthritis (28.2%). Other symptoms reported including: female issues, cancer, hypothyroidism, asthma, kidney problem, inoperable abdomen mass, etc. Out of the 39 caregivers who answered the question about how long they have had the health condition(s), 29 of them reported having some health conditions for over five years (76.9%), whereas 9 of them had that for less than five years (23.1%). The following section provide some descriptive statistics on the psychosocial measures used in this study.

Depressive symptoms. The Patient Health Questionnaire (PHQ-9) was used to assess family caregiver's depression level. The higher the score indicates the more likely for the participants to have severe depressive symptoms. In this study, score of PHQ-9 ranges from 0 to 23, with a mean of 15.56 (*SD*=5.99). At the end of the PHQ-9, there was a question asking the participants to rate how difficult it has been to be able to maintain their normal life. Half of the participants (49.4%) reported it was "somewhat difficult" to manage their personal lives in the past two weeks, whereas 39.5% reported it was "not difficult at all" to manage daily lives.

Perceived stress. The Perceived Stress Scale (PSS) was used to examine family caregivers' perceived stress level, with higher scores suggesting the individual has a higher level of chronic stress. In this study, participants rated their perceived stress level from 7 to 30, with an average of 20.1 (*SD*=4.3).

Caregiver Resources

Coping strategies. Only eight domains (16 items) from the Brief COPE were selected which represented adaptive coping strategies (i.e., Active Coping, Use of Emotional Support, Positive Reframing, Instrumental Support, Acceptance, Planning, Religion, and Humor), with higher score indicates more use of adaptive coping strategies. The total score of this scale ranges between 16 and 64, with a mean of 41.85 (*SD*=9.4). In terms of subscale scores, the highest subscale score was Acceptance (mean= 6.33, *SD*=1.64) whereas the lowest subscale score was Humor (mean=4.24, *SD*=1.9).

Social support. The abbreviated Interpersonal Support Evaluation List (ISEL) has 12 items and is divided into three subscales, with higher score indicates greater perceived availability of support resources. In the present study, the total score ranges from 21 to 43, with a mean of 31.95 (*SD*=3.37).

Quality of Life

The WHOQOL-BREF is scored on four domains: (1) physical health—daily activity, mobility, and work capacity; (2) psychological—negative and positive feelings, and self-esteem; (3) social relationships—personal relationship, social support, and sexual relationship; and (4) environment—financial resources, physical environment, and transportation. The total score of physical related QoL ranges from 7.43 to 20, with a mean of 14.52 (*SD*=2.7). For psychological related QoL, the score range is 7.33 to 20, with an average of 14.19 (*SD*=3.02). Social relationship related QoL has a score range of from 4 to 20, and a mean of 13.22 (*SD*= 3.56), and the last domain, Environmental related QoL, has a score range of from 10.5 to 20, with a mean of 15.25 (*SD*=2.28). Over all QoL has a score range from 39.29 to 79.43, with a mean of 57.08 (*SD*=9.45).

Adults with IDD's Characteristics (see Table 4.2)

Adults with IDD had an average of age of 26.66 (*SD*=9.05) with a range from 18 to 70. Around 45% of the adults with IDD were between the age of 21 and 30, 30% were 20 years old or younger and 18% were between 31 to 40 years old. In terms of diagnosis for the adults with IDD, one-third of the caregivers reported autism spectrum disorder as the primary diagnosis (32.9%), followed by intellectual disability (26.8%), and Down syndrome (20.7%). About a quarter of caregivers reported more than two types of IDD diagnoses, and some of other disabilities category reported by the caregivers include: cerebral palsy, epilepsy, TBI, attentiondeficit/hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), physical disability, etc. For the purpose of this study, the primary diagnosis was regrouped into a three-level variable (ASD, ID, and other DD) for further analysis. The majority of the adults with IDD (95%) were residing with the caregivers at. Whilst, the rest were residing in group homes (2.4%) or lived independently with daily assistance (2.4%). The majority of the adults with IDD (37.8%) were not employed nor in school, while 2.4% of individuals had full-time work (>35 hours per week), 19.5% of individuals had part time work (<35 hours per week), 11% were volunteering, and 29.3% were still in the school system (see Table 4.2).

Table 4. 2
Adults with IDD's characteristics

Variable		*N*	*%*
Age			
	20 and younger	25	30.49%
	21-30	37	45.12%
	31 and older	20	24.39%
Primary Diagnosis			
	ASD	27	32.93%
	ID	12	14.63%
	Other IDD	43	52.44%
Employment Status			
	Have jobs (full time, part time, volunteer)	27	32.93%
	Still in school	24	29.27%
	Unemployed and not in school	31	37.8%
Relationships			
	Parent	74	90.24%
	Other family members	8	9.76%

Functional, independence, and behavioral level. The Waisman Activities of Daily Living Scale (W-ADL) was developed by Maenner et al. (2013) to assess the activity limitations for adolescents and adults with IDD. The total score of W-ADL ranging from 18 to 51, with a mean of 35.21 (*SD*=8.86). The second scale, AADS, was used to assess individual's behavioral issues. The total score of the AADS scales range from 18 to 108, with a mean of 39.70

(*SD*=20.84), with higher score indicates the certain behavior happens more frequently or more difficult to manage. In fact, there are two subscales in this measure. The total score of the first subscale (frequency of behavior) ranges from 9 to 55, with a mean of 20.94 (*SD*=10.6), with higher score indicates the certain behavior happens more frequently. The total score of the second subscale (difficulty in managing) ranges from 9 to 53, with a mean of 18.76 (*SD*=10.48), with higher score indicates more difficult to manage the certain behavior.

Correlational Analysis

Spearman correlation tests were conducted to examine the relationships between ordinal variables (i.e., caregiver's education level, annual household income) and outcome variables (QoL). Pearson correlation tests were used to evaluate the associations between continuous variables (i.e., age of caregivers and age of adults with IDD, functional limitation and behavioral issues of adults with IDD, depressive symptoms, perceived stress level, coping strategies, and social support among caregivers) and QoL. In addition, Multivariate Analysis of Variance (MANOVA) were conducted to assess the relationships between categorical variables (i.e., race/ethnicity, marital status, employment status, caregiver's role, residence status, type of disability of adults with IDD, and health factors of caregivers) and QoL.

Physical related QoL

Physical related QoL was found to have negative correlations with behavioral issues of adults with IDD (r=-.254, p=.036) and caregiver's depressive symptom (r=-.545, p=.0001).

Psychological related QoL

Psychological related QoL was found to be negatively correlated with behavioral issues of adults with IDD (r=-.331, p=.002), caregiver's depressive symptom (r=-.685, p<.001) and perceived stress (r=-.410, p<.001).

Social relationship related QoL

Social support related QoL was found to be negatively correlated with behavioral issues of adults with IDD ($r=-.244$, $p=.036$), caregiver's depressive symptom ($r=-.424$, $p = .0002$) and perceived stress level ($r=-.299$, $p=.0104$).

Environmental related QoL

Environmental related QoL was found to have negative correlations with caregiver's depressive symptom ($r=-.310$, $p=.012$).

Overall QoL

The total score of WHOQOL-BREF was found to be negatively correlated with behavioral issues of adults with IDD ($r=-.321$, $p=.004$), caregiver's depressive symptom ($r=-.627$, $p<.0001$) and perceived stress level ($r=-.386$, $p=.002$).

Other relationships among scales and demographic variables include: behavioral issues of adults with IDD is significantly correlated with age of caregiver ($r=-.362$, $p=.001$), age of adults with IDD ($r=-.340$, $p=.002$), caregiver's depressive symptom ($r=.516$, $p<.001$) and perceived stress level ($r=.384$, $p<.001$). Functional limitation of adults with IDD was found to be negatively correlated with caregiver's coping strategies ($r=-.279$¸ $p=.011$), whereas depressive symptoms is positively correlated with perceived stress ($r=.529$, $p<.001$). In contrast, caregiver's social support was not found to have any relationships with other scales and variables. As for the Spearman correlation test, education level was found to be positively associated with annual household income ($r=.271$, $p=.014$). Table 4.3 depicts the correlation matrix and descriptive statistics of the variables.

Table 4. 3

Correlation, Means, and Standard Deviations for Psychosocial Scales

Variable	1	2	3	4	5	6	7	8	9	10	11
1. Functional Limitation	1	--	--	--	--	--	--	--	--	--	--
2. Behavioral Issues	.130	1	--	--	--	--	--	--	--	--	--
3. Depressive Symptoms	.138	.516**	1	--	--	--	--	--	--	--	--
4. Perceived Stress	.030	.384**	.529**	1	--	--	--	--	--	--	--
5. Coping	-.279*	.031	-.151	.006	1	--	--	--	--	--	--
6. Social Support	-.097	.215	.186	.042	.180	1	--	--	--	--	--
7. Physical related QoL	-.067	-.545**	-.502**	-.292	-.092	-.014	1	--	--	--	--
8. Psychological related QoL	-.095	-.331**	-.685**	-.410**	.190	-.083	.503**	1	--	--	--
9. Social relationship related QoL	.028	-.424**	-.373**	-.299*	.136	-.024	.361**	.684**	1	--	--
10. Environmental related QoL	-.007	-.310*	-.359**	-.198	.064	.113	.458**	.535**	.469**	1	--
11. Overall QoL	-.042	-.627**	-.612**	-.386**	.104	-.013	.712**	.874**	.823**	.742**	1
Mean	35.21	39.70	15.56	30.15	41.85	31.95	14.51	14.19	13.22	15.25	57.05
SD	8.86	20.84	5.99	4.40	9.40	3.37	2.70	3.02	3.56	2.28	9.45
Min	18.0	18.0	9.0	17.0	16.0	21.0	14.43	7.33	4.00	10.50	39.29
Max	51.0	108.0	32.0	40.0	64.0	43.0	14.59	20.00	20.00	20.00	79.43

Spearman Correlation

Variable	12.	13.
12. Highest Education	1	--
13. Annual Household income	.271*	1
Mean	5.67	5.27
SD	1.85	2.28
Min	1	1
Max	10	8

Note: **p*≤.05; ***p*≤.01.

The results of MANOVA tests show that none of the variables were significantly related with any outcome variables, which indicates that this test is not appropriate to use. Thus, separate ANOVA tests were conducted to examine whether there was any group difference (see Table 4.4). The result of the ANOVA tests showed caregiver's physical related QoL ($F(1, 81)=4.22$, $p=.024$) and psychological related QoL ($F(1, 81)=3.5$, $p=.031$) differ between those who had and did not have secondary health conditions. Also, caregivers with different residence status and roles were found to have different psychological related QoL, with $F(1, 81)=13.5$, $p=.0003$, and $F(1, 81)=17.5$, $p<.0001$, respectively. Finally, employment status of the caregivers had borderline significance association with psychological related QoL, with $F(1, 81)=3.01$, $p=.050$.

Table 4. 4
Results of ANOVA tests

	Dependent Variable	*F*	*p*
Race	Physical related QoL	0.24	.580
	Psychological related QoL	0.15	.695
	Social relationship related QoL	1.34	.250
	Environmental related QoL	0.55	.451
	Overall QoL	0.01	.502
Marital status	Physical related QoL	0.11	.531
	Psychological related QoL	2.85	.092
	Social relationship related QoL	0.00	.604
	Environmental related QoL	1.59	.197
	Overall QoL	0.00	.562
Have health condition or not	Physical related QoL	4.22	**.024***
	Psychological related QoL	0.35	**.031***
	Social relationship related QoL	0.73	.466
	Environmental related QoL	0.37	.434
	Overall QoL	0.95	.388
Residence status	Physical related QoL	0.76	.288
	Psychological related QoL	13.5	**<.0001****
	Social relationship related QoL	1.96	.163
	Environmental related QoL	3.69	.064
	Overall QoL	3.49	.069
Caregiver role	Physical related QoL	0.01	.371
	Psychological related QoL	17.5	**<.0001****
	Social relationship related QoL	3.86	.064
	Environmental related QoL	0.036	.383
	Overall QoL	2.85	.098
Employment status (caregiver)	Physical related QoL	1.86	.170
	Psychological related QoL	3.01	.0503
	Social relationship related QoL	0.70	.420
	Environmental related QoL	0.33	.535
	Overall QoL	1.11	.330
IDD types	Physical related QoL	0.13	.647
	Psychological related QoL	2.88	.057
	Social relationship related QoL	0.77	.443
	Environmental related QoL	0.03	.706
	Overall QoL	0.41	.624
Employment status (adults with IDD)	Physical related QoL	1.07	.320
	Psychological related QoL	0.28	.758
	Social relationship related QoL	0.14	.778
	Environmental related QoL	0.18	.435
	Overall QoL	0.16	.770

Hierarchical Regression Analysis

To answer research question #2, hierarchical regression analysis (HRA) was conducted to predict the outcome variable (i.e., QoL) by entering three sets of IVs into the regression model. HRA was conducted in pre-determined steps: (1) demographic variables; (2) caregiver's health status (depression and perceived stress level); (3) caregivers' resources (coping strategies and social support). According to the results of the correlational analyses, only predictor variables which showed significant associations with QoL would be entered into the regression model. For those which are not significantly correlated with QoL were deleted from the model.

More specifically, in **Step 1**, behavioral issues and functional limitation of adults with IDD, the age of caregivers, and the age of adults with IDD were entered. In **Step 2**, caregiver's depressive symptoms and perceived stress level were entered. In addition, given the significant correlations between caregivers' health conditions and Physical related QoL, this variable was therefore entered for Regression Model for physical related QoL and psychological related QoL. Caregiver and care-recipient's residency status was entered for Regression Model for Psychological related QoL only, based on its significant correlation. And in the **Step 3**, two IVs (caregiver's coping strategies and social support) were designed to be entered into the model in this last step based on the study design, thus in this step these two variables were entered into the models. Table 4.5 summarizes the variables entered in the modified regression model compared to the original model.

Table 4. 5

Variables to be entered in Original versus Modified Hierarchical Regression Model

	Original	**Modified**
Step 1	Caregiver: age, race/ethnicity, education level, annual household income, marital status, employment status, caregiver role, residence status Adults with IDD: age, type of IDD, behavioral issues, functional independence level, employment status	Caregiver: age Adults with IDD: age, behavioral issues, functional independence level
Step 2	Caregiver's depressive symptoms and perceived stress level, health condition	• Caregiver's depressive symptoms, perceived stress level • Health conditions only for Physical and Psychological related QoL • Residency status only for Psychological related QoL
Step 3	Caregiver's coping skills, social support	Caregiver's coping skills, social support

The final regression model of each outcome variable is presented below, starting with the overall QoL, then each of the four domains (physical related, psychological related, social relationship related and environmental related QoL). Normality of residuals was examined using P-P plots and histogram of the residuals. All P-P Plots and histograms indicate that residuals have a distribution that can be reasonably assumed to be normal. The results of the HRA are presented in Table 4.6, which include values of changes in $R^2 (\Delta R^2)$, unstandardized regression coefficients (B), standard errors (SE B), and standardized coefficients (β) for the predictor variables at each step and in the final model.

Regression Model for Overall QoL

All variables accounted for 41% of variance in caregiver's overall QoL score, which indicates a good support of using the theoretical framework, with R^2=.411, F(8, 73)= 6.36, p< .0001. This model focused on the overall QoL of caregivers. In step 1, the characteristics of caregivers and adults with IDD were entered into the model, which accounted for 13.5% of variance in caregiver's overall QoL (R^2 =.135, *F*(4, 77)= 3.00 *p*=.023). After examining the standardized partial regression coefficients, behavioral issues of adults with IDD showed significant contribution to the change in variance in overall QoL, with *β*=-.384, *t*(81)=-3.24. In step 2, the caregivers' health related variables accounted for 27% of variance (R^2 =.403, F(6, 75)=8.44, *p*<.0001), a significant amount of the additional variance in overall QoL beyond that has been explained by the characteristics of caregivers and adults with IDD variables entered in the first step. Only depressive symptoms of caregivers was found to have significant contribution to the change in variance in caregivers' overall QoL, with *β*=-.575, t(81)=-4.91, *p*<.0001. In step 3, the change of R^2 was insignificant after the caregiver resource variables were entered, indicating that coping strategies and social support did not contribute to the variance of caregivers' overall QoL. In the final model, only caregiver's depressive symptoms (*β*=-.587, t(81)=-4.844, *p*<.0001) was found to be significant contributor to the variance in overall QoL score, when other variables were held constant.

Table 4. 6
Hierarchical Multiple Regression Analysis for Prediction (Overall QoL)

			At Entry into Model			Final Model		
Variable	R^2	ΔR^2	B	SEB	*β*	B	SEB	*β*
Step 1	.135	**.135***						
Caregiver age			-.161	.120	-.167	-.104	.105	-.108
Adults with IDD age			.048	.121	.049	.131	.105	.133
Functional limitation			.014	.120	.014	.045	.097	.045
Behavioral issues			-.164	.051	**-.384****	-.010	.053	-.025
Step 2	.403	**.268****						
Depression			-.854	.174	**-.575****	-.872	.180	**-.587****
Stress			-.182	.221	-.090	-.163	.224	-.080
Step 3	.411	.008						
Coping			.005	.092	.005	.005	.092	.005

Social support	.242	.254	.091	.242	.254	.091

Step 1: $F(4,77)=3.00$, $p=.023$; *Step 2:* $F(6,75)=8.44$, $p<.0001$; *Step 3:* $F(8,73)=6.36$, $p<.0001$

Regression Model for Physical Health Related QoL

Around 44% of variance ($R^2 = .439$, $F(10, 71)=5.55$, $p<.0001$) in the physical related QoL score among caregivers can be accounted by the three sets of predictor variables. In step 1, the characteristics of caregivers and adults with IDD were entered into the model, which accounted for 15% of variance in physical related QoL, with $R^2 = .153$, $F(4, 77)= 3.48$, $p<.05$. Caregiver's age and adults with IDD's behavioral issues of adults with IDD were found to be significant contributors to the change in variance in caregiver's physical health aspect of QoL, with $\beta=-.303$, $t(81)= -2.45$, $p=.017$ and $\beta= -.382$, $t(81)= -3.26$, $p=.002$, respectively. It should be noted that both variables had negative relationships with the outcome variable, indicating that caregivers who were older and cared for adults with IDD who had higher functional limitation level would have lower physical related QoL. In step 2, caregivers' health related variables were entered. Again, the caregivers' health related variables accounted for 25% of variance ($R^2 = .402$, $F(8, 73)= 6.18$, $p<.0001$), a significant amount of the additional variance in physical related QoL beyond that has been explained by the characteristics of caregivers and adults with IDD variables entered in the first step . While caregiver age remained significant in this step, functional limitation became insignificant with the addition of the caregivers' health related variables ($\beta=-.115$, $t(81)=-.93$, $p=.354$). In contrast, caregiver's depressive symptoms was found to have significant contribution to the change in variance, with $\beta=-.498$, $t(81)=-4.19$, $p<.0001$. Caregiver's health condition also significantly correlated with their physical related QoL ($\beta=.296$, $t(81)= 2.63$, $p<.05$); however, caregiver's perceived stress level was not significant contributor in this step, with its $\beta=.034$, $t(81)=.30$, $p=.763$. In step 3, the change in variance was insignificant after the caregiver resource variables were entered, indicating that coping strategies and social support did not contribute to the variance of caregivers' physical related QoL. In the final model, both caregiver's depressive symptoms caregiver's health conditions are significant contributors to physical health related QoL, with $\beta=.226$, $t(81)= 2.26$, $p<.05$ and $\beta=-.556$, $t(81)=-4.63$, $p<.0001$, respectively, when other variables were held constant.

Table 4. 7
Hierarchical Multiple Regression Analysis for Prediction (Domain 1: Physical Health Related QoL)

			At Entry into Model			Final Model		
Variable	R^2	ΔR^2	B	SEB	β	B	SEB	β
Step 1	.153	**.153***						
Caregiver age			-.082	.034	**-.303***	-.058	.030	-.212
Adults with IDD age			.006	.034	.022	.007	.030	.026
Functional limitation			.001	.004	.005	-.004	.027	-.013
Behavioral issues			-.046	.014	**-.382****	-.016	.015	-.121
Step 2	.404	**.251****						
Depression			-.209	.050	**-.498****	-.233	.050	**-.556****
Stress			.019	.064	.034	.032	.064	.056
Health condition			1.148	.479	**.296****	10128	.500	**.226***
Step 3	.439	.035						
Coping			-.050	.027	-.189	-.050	.027	-.189
Social support			0.099	.072	.133	0.099	.072	.133

Step 1: $F(4, 77)=3.48$, $p=.011$; *Step 2:* $F(8, 73)=6.18$, $p<.0001$; *Step 3:* $F(10, 71)=5.55$, $p<.0001$

Regression Model for Psychological Health Related QoL

About 50% of variance in the psychological related QoL score among caregivers can be explained by the three sets of predictor variables. In step 1, the characteristics of caregivers and adults with IDD accounted for 12% of variance in caregiver's psychological health aspect of QoL, with $R^2 = .118$, $F(4, 77)=2.59$, $p=.043$. Only adults with IDD's behavioral issues level was found to have significant contribution to the change in variance in psychological related QoL, with β=-.357, $t(81)$=-2.98, p=.004. The negative relationship between behavioral issues and psychological related QoL indicates that caregivers for adults with IDD who had more behavioral issues would have lower psychological health related QoL. In step 2, caregivers' health related variables were entered. Similar to findings for physical related QoL, the caregivers' health related variables accounted for 48% of variance (R^2=.489, F(8, 73)=8.72, p<.0001), a significant amount of the additional variance in psychological related QoL beyond that has been explained by the characteristics of caregivers and adults with IDD variables entered in the first step. In this step, behavioral issues became insignificant predictor with the addition of the caregivers' health related variables. Caregiver's depressive symptoms was then found to be significant contributor to the change in variance, with β=-.690, $t(81)$=-6.27, p<.0001. However, no significant was found in caregiver's perceived stress level or caregiver's health conditions. In step 3, the change in variance was insignificant after the caregiver resource variables were entered, indicating that coping strategies and social support did not contribute to the variance of caregivers' psychological related QoL. In the final model, only caregiver's depressive symptoms was found to be significant predictor, with β=-660, t(81)=-5.83, p<.0001, when other variables were held constant.

Table 4. 8

Hierarchical Multiple Regression Analysis for Prediction (Domain 2: Psychological Health Related QoL)

			At Entry into Model			Final Model		
Variable	R^2	ΔR^2	B	SEB	β	B	SEB	β
Step 1	.118	**.118***						
Caregiver age			-.028	.041	-.087	.006	.035	.017
Adults with IDD age			.000	.041	.001	.027	.035	.081
Functional limitation			-.218	.638	-.038	.062	.523	.011
Behavioral issues			-.930	.312	**-.357****	.192	.301	.074
Step 2	.489	**.370****						
Depression			-3.129	.499	**-.690****	-2.992	.514	**-.660****
Stress			-.425	.705	-.603	-481	.711	-.070
Health condition			.161	.447	.359	.307	.469	.060
Residency status			.660	.061	.674	.924	.086	.926
Step 3	.503	.014						
Coping			.681	.133	1.387	.681	.133	1.387
Social support			-.004	.000	-.004	-.004	.000	-.004

Step 1: F(4,77)= 2.59, *p*=.043; *Step 2: F*(8,73)=8.72, *p*<.0001; *Step 3: F*(10,71)=7.18, *p*<.0001

Regression Model for Social Relationships Related QoL

Around 20% of variance in social relationship related QoL score among caregivers can be accounted by the three sets of predictor variables, with R^2=.198, *F*(8, 73)=2.25, *p*=.033. In step 1, the change in variance was insignificant after the demographic covariates were entered into the model, indicating that the characteristics of caregivers and adults with IDD did not contribute to the variance in caregivers' social relationship related QoL. In step 2, after controlling the demographic covariates from step 1, the caregivers' health related variables accounted for an additional 11% of variance (R^2=.180, *F*(6, 75)=2.74, *p*=.019), a significant amount of the additional variance in social relationship related QoL beyond that has been explained by the demographic covariates entered in the first step. Again, only caregiver's depressive symptoms was found to have significant contribution to the change in variance, with *β*=-.368, *t*(81)=-2.68, *p*=.009. In step 3, the change in variance was insignificant after the caregiver resource variables were entered, indicating that coping strategies and social support did not contribute to the variance of caregivers' psychological related QoL. In the final model, only caregiver's depressive symptoms was found to have a significant contribution to social relationship related QoL, with *β*=-.359, *t*(81)=-2.54, *p*=.013.

Table 4. 9

Hierarchical Multiple Regression Analysis for Prediction (Domain 3: Social Relationship Related QoL)

			At Entry into Model			Final Model		
Variable	R^2	ΔR^2	B	SEB	*β*	B	SEB	*β*
Step 1	.069	.069						
Caregiver age			-.018	.047	-.051	-.003	.046	-.009
Adults with IDD age			-.004	.047	-.011	.015	.046	.041
Functional limitation			.016	.043	.043	.035	.043	.092
Behavioral issues			-.045	.020	**-.283***	-.011	.023	-.071
Step 2	.180	**.111***						
Depression			-.206	.077	**-.368****	-.201	.079	**-.359***
Stress			-.047	.098	-.061	-.045	.099	-.059
Step 3	.198	.018						
Coping			.034	.041	.094	.034	.041	.094
Social support			.090	.112	.091	.090	.112	.091

Step 1: F(4,77)=1.42, *p*=.236; *Step 2: F*(6,75)=2.74, *p*=.019; *Step 3: F*(8,73)=2.25, *p*=.033

Regression Model for Environmental Related QoL

About 17% of the environmental related QoL score among caregivers can be explained by the three sets of predictor variables, with R^2=.175, F(8, 73)=1.93, *p*=.068. In step 1, the change in variance was insignificant after the demographic covariates were entered into the model, indicating that the characteristics of caregivers and adults with IDD did not contribute to the variance in caregivers' environmental aspect of QoL. In step 2, after controlling the demographic covariates from step 1, the caregivers' health related variables accounted for an additional 10% of variance (R^2 =.13, F(6, 75)=1.86, *p*=.099), a significant amount of the additional variance in environmental related QoL beyond that has been explained by the demographic covariates entered in the first step. Again, only depressive symptoms among caregivers was found to have significant contribution to the change in variance in caregivers' environmental related QoL, with *β*=-.358, *t*(81)=-2.53, *p*=.013. In step 3, the change in variance was insignificant after the caregiver resource variables were entered, indicating that coping strategies and social support did not contribute to the variance of caregivers' psychological related QoL. In the final model, only caregiver's depressive symptoms was found to have a significant contribution to social relationship related QoL, with *β*=-.389, *t*(81)= -2.71, *p*=.008.

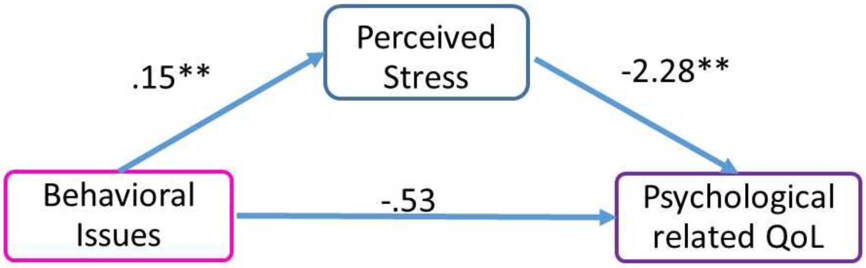
Table 4. 10
Hierarchical Multiple Regression Analysis for Prediction (Domain 4: Environmental Related QoL)

			At Entry into Model			Final Model		
Variable	R^2	ΔR^2	B	SEB	*β*	B	SEB	*β*
Step 1	.028	.028						
Caregiver age			-.007	.031	-.028	.003	.030	.014
Adults with IDD age			.032	.031	.136	.039	.030	.166
Functional limitation			-.002	.028	-.009	.009	.028	.036
Behavioral issues			-.008	.013	-.080	.010	.015	.101
Step 2	.130	**.102***						
Depression			-.129	.051	**-.358***	-.140	.052	**-.389****
Stress			-.023	.064	-.048	-.011	.064	-.023
Step 3	.174	.44						
Coping			.001	.026	.003	.001	.026	.003
Social support			.142	.073	.223	.142	.073	.223

Step 1: F(4,77)=.55, *p*=.697*; Step 2: F*(6,75)=1.86, *p*=.099*; Step 3: F*(8,73)=1.93, *p*=.068

Mediation Analyses

Figure 7: The single-mediation model of the effect of behavioral issues on psychological health related quality of life, with perceived stress being the mediator



Total effect model: *p*=.001**

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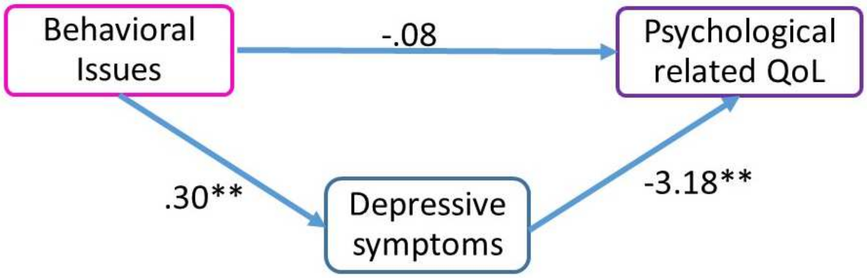
Figure 8: The single-mediation model of the effect of behavioral issues on psychological health related quality of life, with depressive symptoms being the mediator.



Total effect model: *p*<.000**

To answer research question #3, mediation analysis was used to determine whether caregivers' mental health conditions (depressive symptoms and perceived stress level) mediate the relationship between adults with IDD's behavioral issues and psychological related QoL among caregivers of adults with IDD. Two single mediation analyses were conducted using SPSS macro set, PROCESS (Hayes, 2016). Results for mediation analyses are presented in Table 4.1 and 4.12.

Table 4. 11

Results of Mediation Analysis -1: The effect of behavioral issues on psychological health related quality of life, with perceived stress being the mediator

IV to Mediators (caregiver's perceived stress**)**

Outcome: Caregiver's perceived stress
Predictor: Behavioral issues of adults with IDD

Model Summary	R	R^2	MSE	F	df	p
	.3836	.1471	.1668	13.80	1, 80	**.0004****

	b	SE b	t	p	LLCI	ULCI
Behavioral issues	.1456	.0392	3.7148	.0004	.0676	.2236

Direct Effects of Mediators on DV

Outcome: Psychological related QoL
Predictor: Behavioral issues of adults with IDD
Mediator: Caregiver's depressive symptoms

Model Summary	R	R^2	MSE	F	df	p
	.4508	.2032	7.4394	10.06	2, 79	**.0001****

	b	SE b	t	p	LLCI	ULCI
Caregiver's perceived stress	-.2.277	.7467	-3.0492	.0000	18.012	26.4284
Behavioral issues	--.5308	.2834	-1.8730	.0648	-1.0949	.0333

Direct Effect of IV on DV

	Effect	SE	t	p	LLCI	ULCI
Perceived stress	-.5308	.2834	-1.8730	.0648	-1.0949	.0333

Indirect Effect of IV on DV

	Effect	Boot SE	Boot LLCI	Boot ULCI
Perceived stress	-.3315	.1348	-.6718	-.1120

Table 4. 12

Results of Mediation Analysis -2: The single-mediation model of the effect of behavioral issues on psychological health related quality of life, with depressive symptoms being the mediator

IV to Mediators (caregiver's depression**)**						
Outcome: Caregiver's depression Predictor: Behavioral issues of adults with IDD						
Model Summary	*R*	R^2	MSE	*F*	*df*	*p*
	.3836	.1471	.1668	13.80	1, 80	__.0004**__
	b	SE *b*	t	*p*	LLCI	ULCI
Behavioral issues	.1456	.0392	3.7148	.0004	.0676	.2236
Direct Effects of Mediators on DV						
Outcome: Psychological related QoL Predictor: Behavioral issues of adults with IDD Mediator: Caregiver's depressive symptoms						
Model Summary	*R*	R^2	MSE	*F*	*df*	*p*
	.4508	.2032	7.4394	10.06	2, 79	__.0001**__
	b	SE *b*	t	*p*	LLCI	ULCI
Caregiver's perceived stress	-.2.277	.7467	-3.0492	.0000	18.012	26.4284
Behavioral issues	--.5308	.2834	-1.8730	.0648	-1.0949	.0333

Direct Effect of IV on DV

	Effect	SE	*t*	*p*	LLCI	ULCI
Perceived stress	-.5308	.2834	-1.8730	.0648	-1.0949	.0333

Indirect Effect of IV on DV

	Effect	Boot SE	Boot LLCI	Boot ULCI
Perceived stress	-.3315	.1348	-.6718	-.1120

In the first mediation analysis, by regressing caregiver's perceived stress (M1) on behavioral issues (IV) of adults with IDD, it was found that they significantly associated with each other, with *b*=.15, *t*(81)=3.71, *p*<.001. The mediator (caregiver's perceived stress) was significantly associated with psychological related QoL, while statistically controlling for the behavioral issues of adults with IDD (DV). This model accounted for 20% of the variance in psychological related QoL, R^2 =.2032, *F*(2, 79)=10.08, *p*<.000, and is considered a large effect size (Cohen, 1988; 1992). Based on the result, behavioral issues of adults with IDD, caregiver's perceived stress, and psychological related QoL all had significant relationships with each other, thus the mediation analysis could be employed. The result also shows that behavioral issues of adults with IDD and mediators (i.e., caregiver's perceived stress) can predicting psychological related QoL, the existence of this mediator actually made behavioral issues of adults with IDD no longer predicts psychological related QoL, *b*=.28, *t*(79)=-1.87, *p*=.06, >.05.

The second mediation analysis regressing caregiver's depressive symptom on behavioral issues of adults with IDD. It was also found that they significantly associated with each other, with *b*=.30, t(81)=5.37, *p*<.001. This mediator (i.e., caregiver's depressive symptom) was significantly associated with caregiver's psychological related QoL, while statistically controlling for the behavioral issues of adults with IDD. The overall model accounted for 47% of the variance, R^2=.4708, *F*(2, 79)=35.14, *p*<.000, and is considered as a large effect size (Cohen, 1988; 1992). This result also shows that behavioral issues of adults with IDD and caregiver's depressive symptom can predict caregiver's psychological related QoL, and the existence of this mediator (i.e., caregiver's depressive symptom) also made behavioral issues of adults with IDD no longer predicts psychological related QoL among caregivers, *b*=.08, t(81)=.32, *p*=.75, >.05.

In summary, the two mediators were significant as predicted, yielding support for the proposed mediation models. However, the findings only support a sole-mediation model, rather than a dual-mediation model, thus two single mediation analyses were employed rather than one dual-mediation analysis. The findings conform to the predictions of a model in which behavioral issue is associated with psychological related QoL indirectly through its association with caregiver's perceived stress and depressive symptoms, respectively. In addition, the association between behavioral issues and psychological related QoL in the final regression equation became non-significant after controlling for the effect of the mediators. This pattern of findings, with significant indirect effects through one or more mediators accompanied by insignificant direct effects, is not uncommon and was characterized by Baron and Kenny (1986) as a case of complete mediation (i.e., depressive symptoms help to explain the relationship between behavioral issues and psychological related QoL completely.)

Test of Indirect Effect

Indirect effect is a measure of how much of the behavioral issues of adults with IDD on QoL that was being mediated. It also reflects how much the amount of total effect of the behavioral issues of adults with IDD decreases when mediators (caregiver's depressive symptoms and perceived stress level) are in each model. For both sole-mediation analyses, the significance of the indirect effect was both obtained from 1,000 bootstrap resamples, with a 95% of confidence interval (CI) and the CI does not include zero. For mediation model 1 and 2, as expected, the unstandardized indirect effects (with 95% CIs derived from bias-corrected and accelerated bootstrap procedures) were products (**ab**) = -0.33 (-.67, -0.11) and -0.94 (-1.38, -.06) for the indirect paths through perceived stress (mediation analysis-1) and depressive symptoms (mediation analysis-2), respectively. Given that the individual paths **a** and **b** were significant for both mediators (perceived stress and depressive symptoms), the 95% CIs do not include zero indicating that the indirect effect are significant (p<.05) for both mediators. In other words, the test results showed that caregiver's perceived stress and depressive symptoms both had a significant indirect effect on the relationship between behavioral issues of adults with IDD and psychological aspect of QoL.

In sum, caregiver's perceived stress and depressive symptoms were found to fully mediate the association between behavioral issues of adults with IDD and psychological related QoL, as evidenced by the non-significant main effect of behavioral issues of adults with IDD when caregiver's perceived stress and depressive symptoms and perceived stress were entered in the model, yielding support for the mediation model.

CHAPTER 5

DISCUSSION

The purposes of this chapter are to describe and interpret the findings of the study, and provide implications of the results. Suggestions for future research and limitations of the study are also provided at the end of this chapter. This study is not the first one examining the Quality of Life (QoL) among family caregivers; however, it is the first study proposing a theoretical framework based on previous studies and examining the comprehensive aspects of family caregivers of adults with IDD using the framework.

The General Research Findings

The lack of understanding of the needs among the family caregivers of adults with IDD makes it very difficult to provide suitable services and to locate useful resources for the family. The primary goal of this study was to test the proposed theoretical model and evaluate its ability to predict family caregivers' perceived QoL when they care for adults with IDD through the use of hierarchical regression analysis. The study served a purpose of presenting a broader and more comprehensive exploration of the QoL of family caregivers of adults with IDD. In addition, this study also tested if various factors (i.e., health status and caregiver resources) can mediate the relationship between behavioral issues of adults with IDD and caregivers' perceived QoL through mediation analyses.

Relationships between Demographic Variable and Caregiver's QoL

In this study, correlational analyses were conducted to examine the relationships between demographic variables of both the caregivers and adults with IDD, and the main outcomes (caregiver's perceived overall QoL as well as physical, psychological, social relationship and environmental related QoL). Several significant relationships were found. For example, physical and psychological related QoL, and the overall QoL were found to be significantly correlated with adults with IDD's behavioral issues, caregiver's depressive symptoms, and the caregiver's perceived stress level. In other words, the more behavioral issue adults with IDD exhibit and/or more depressive symptoms or perceived stress caregivers experience, the lower caregiver's physical, psychological, and overall QoL would be. Social relationship related QoL was also found to have significant associations with caregiver's depressive symptoms and perceived stress, while environmental related QoL was found a negative relationship with caregiver's depressive symptoms.

Other scales also were found to have significant relationships with demographic variables. Specifically, adults with IDD's behavioral issues was highly correlated with age of caregivers and age of adults with IDD, it was also highly correlated with depressive symptoms and perceived stress among family caregivers. Functional limitation of adults with IDD was found to have negative relationship with caregiver's coping strategies, whereas caregivers' depressive symptoms was found to positively correlate with their perceived stress level.

Aging caregivers may also experience stress from other resources, such as their own health conditions and other changes in their lives, including their marital status or employment status (Chou et al., 2011). Almost half of the study participants reported to have at least one health condition. In the current study, arthritis is the most commonly reported health condition. Other health conditions reported by caregivers include high blood pressure, back pain, and depression, and this result was similar to the result of a previous study that osteoarthritis was found to be one of the health conditions reported by the aging caregivers and could have impact on their capacity to continue providing care (Haley & Perkins, 2004b). Based on the ANOVA tests, having health conditions actually correlated with their physical and psychological related

QoL. In other words, caregivers would have lower physical and/or psychological related QoL if they reported to have health conditions.

However, most of the demographic variables were not found to be accounted for the variance in the outcome variables. For example, previous studies have indicated that race/ethnicity might result in different level of depressive symptoms among caregivers that Anglo mothers of adults with IDD were found to have lower self-reported depressive symptoms than Latino mothers (Blacher & McIntyre, 2006), and Black caregivers were found to be more resilient to negative situations than White caregivers (Haley et al., 1995). In the current study, the majority of the caregivers were White (86.6%) so that it was not possible to compare different racial/ethnic groups. In conclusion, perceived levels of QoL for family caregivers had little to do with their demographic characteristics.

Social Relationship and Environmental Related QoL As Outcomes

Similar to caregiver's physical and psychological related QoL, Social relationship and Environmental related QoL were also found to be significantly correlated with behavioral issues of individuals with IDD and caregiver's depressive symptom. Besides, caregiver's perceived stress was also found to have significant relationship with caregiver's Social relationship related QoL. Surprisingly, social support as measured by the Interpersonal Support Evaluation List (ISEL) was not found to be correlated with social relationship related QoL. The operational definition of social relationship related QoL, as described in the WHOQOL-BREF manual, covers personal relationships, social support, and sexual behavior and the ISEL measures appraisal (perceived availability of someone they can talk to about problems they are facing), belonging (availability of people they can do things with), and tangible support (availability of material aid) (Cohen et al., 1985). Although these domains are all part of so-called social support, the fact that the ISEL does not cover the exact same aspects as WHOQOL-BREF's social relationship related QoL might contribute to the insignificant relationship between the two scales.

Based on the Hierarchical regression model, predictor variables were not able to predict environmental related QoL among caregivers. In fact, the operational definition of environmental related QoL, as described in the WHOQOL-BREF manual, covers the most aspects than the other three domains. Financial resources, freedom, physical safety and security, health and social care (accessibility and quality), home environment, opportunities for acquiring new information and skills, participation in and opportunities for recreation (leisure activities), physical environment (pollution/ noise/ traffic/ climate), and transport, are all considered as environmental related QoL. However, most of these areas were not discussed or chosen as variables in the current study. This might result in the lack of significant relationships with the predictor variables.

Behavioral Issues and Independence Level of Adults with IDD as Predictors

Maternal depressive symptoms were recognized to be highly correlated with behavioral problems in children with ASD (Feldman et al., 2007). Besides, children's social deficits were also found to be related to depressive symptoms and parental stress (Serrata, 2012). The present study further confirmed that behavioral issues of adults with IDD were negatively correlated with family caregivers' physical health- and psychological health-related QoL, as well as the overall QoL.

Studies of children with IDD and their family caregivers indicated that care recipients' ADL functionality and the required demands could lead to higher level of caregiver burden. However, in this study, independence level of adults with IDD did not correlate with caregivers'

QoL. This result can be explained by the “adaptation” theory, which refers that these caregivers were more experienced and adapted to the caregiving demand after providing care for family members with IDD for longer period compared to caregivers of younger children with IDD (Caldwell, 2008; Chou et al., 2011; Heller et al., 2007).

Individuals with IDD’s residence status (i.e., residing with the caregiver or not) were found to be related to caregiver’s psychological related QoL, which concurred with the hypothesis of the present study and also echoed with previous studies that when caregivers co-resided with their adult child with IDD, the caregivers would show significant increases in depressive symptoms, negative mental health status, and poorer health related QoL (Krauss et al., 2005; Seltzer et al., 2004).

Depressive Symptoms and Perceived Stress as Predictors

Only variables which showed relationships with overall and four subdomains of QoL were included in the five separate regression models. Among the five regression models, the most promising one is the regression model for psychological related QoL as the dependent variable, which accounted for 49% of variance in psychological related QoL among family caregivers. This is considered as large effect size based on Cohen (1992), and the model demonstrates to have good supports in predicting psychological related QoL for caregivers. The results suggested that age of caregivers and adults with IDD, adults with IDD’s behavioral issues, caregivers’ mental health status (depressive symptoms and perceived stress), and caregivers’ coping strategies and social support, all accounted for the variance in psychological related QoL. Other models, such as the regression model for physical related QoL and regression model for overall QoL, also demonstrate significant support in predicting the outcomes.

Caregiver's mental status, particularly depressive symptoms and perceived stress were both found to be negatively correlated with the physical, psychological, and overall QoL among family caregivers in this study, which means that the higher caregiver's depressive symptoms and perceived stress were, the lower their QoL was. Stressors and depression symptoms which were identified to be related to parental stress when caring for children with ASD include: child's social skill deficits, sleep disturbance, and familial, marital, and financial stresses (Serrata, 2012). Depressive symptoms were found to be very common among mothers of children, adolescents, and young adults with IDD (Abbeduto et al., 2004; Feldman et al., 2007) and were also confirmed in this study among caregivers of adults with IDD.

In the present study, it is also confirmed that family caregivers for adults with IDD showed higher levels of depressive symptoms and perceived stress, which is similar to those caregivers for children with IDD. This result indicates that depressive symptoms are common for caregivers of younger population, and it can also be applied to caregivers of older population with IDD. Depressive symptoms among caregivers was also found to be significantly related to all domains of QoL as measured by WHOQOL-BREF, perceived stress, and behavioral issues of adults with IDD. In fact, caregivers' depressive symptoms were so significantly correlated with outcomes that it overshadowed other variables' effects on the QoL.

The result of this study is similar to numerous studies that stress related to providing care for individuals with IDD usually had impact on caregiver's health condition and their overall functioning, including recreational activities, household chores, financial issues, physical and psychological functioning, marital satisfaction, sibling relationships, and relationships with other family members (Higgins et al., 2005; Raina et al., 2004). As a matter of fact, Dillenburger and McKerr (2010) specifically pointed out that caregivers tend to worry about the future plans for their adult child with IDD, which could result in higher anxiety and higher stress level. In the present study, although residential status did not show any direct correlation with caregiver's depressive symptoms, it did show significant relationship with caregiver's psychological related QoL, which means this co-residence status could strongly impact caregiver's psychological related QoL.

In addition to these findings, many variables which were anticipated to have impact on the outcomes were in fact not significant, and it was speculated that the relationships between depressive symptoms and outcome variables were too salient that it might overshadow other predictor variables' effect on the outcome variables. Future exploration should consider comparing different models with or without depressive symptoms and see how much effect depressive symptoms has on not only outcome variables but other variables as a whole.

Mediation Effects on Quality Of Life

In this study, mediation effects were analyzed to further examine associations between variables. The results indicated that behavioral issues of adults with IDD impacted mental health (depressive symptoms and perceived stress level) among family caregivers and their psychological related QoL, while mental health of the caregivers also impact their psychological related QoL. When caregiver's mental health is taken care of, their psychological related QoL can still be maintained even when they have to provide care to adults with IDD who had behavioral issues. In other words, just as predicted, caregiver's depressive symptoms and stress level could each mediate the relationship between adults with IDD's behavioral issues and psychological related QoL. This result is similar to many past studies that stress originated from providing care for individuals with IDD can have impact not only on caregiver's' health condition, but also on their overall functioning, including recreational activities, household chores, financial issues, physical and psychological functioning, marital satisfaction, sibling relationships, and relationships with other family members (Higgins et al., 2005; Raina et al., 2004).

In the present study, the results suggest that family caregivers’ mental health status should be evaluated and emphasized especially for the caregivers of adults with significant behavioral issues, since these two factors were highly correlated to the caregiver's’ psychological aspect of QoL. The findings also suggest that caring for adults with IDD with more behavioral issues does not necessarily relate to having lower psychological aspect of QoL, as long as they have good mental health status, and their mental capacity of caring for adults with IDD who had significant behavioral issues could be extended. Improving caregivers’ overall mental health could also decrease their depressive symptoms and perceived stress, and thus further improve their psychological QoL.

Summary

The factors in the present study proven to be correlated with caregivers of children with IDD would also be applicable to aging caregivers of adults with IDD. The results of this study showed that adults with IDD’s behavioral issues, and caregivers’ depressive symptoms and their perceived stress level will affect the caregivers’ QoL, which echoed with the literature. While not all but some of the demographics information associates with aging caregivers’ QoL, as well as their caregiving demands and health issues. This study demonstrates that the proposed conceptual framework in is useful in predicting different aspects of QoL among aging caregivers of adults with IDD. Mediation analyses further suggests that caregivers’ depressive symptoms fully mediate the relationship between behavioral issues of adults with IDD and caregiver’s psychological related QoL. The results reveal the importance of mental health status while caring for adults with IDD who have severe behavioral issues. This study shed light on the fact that one-fit-all service might not be applicable to all age groups of caregivers and individuals with IDD. It is indeed important to consider both the similarities and differences as well as providing unique services to aging caregivers of adults with IDD in order to optimize the service outcomes.

Strengths and Limitations of the Research

This research is unique among other similar studies. This is one of the few studies really focused on the family, instead of the individuals with IDD while most other studies looked at the individual with IDD, instead of the whole family. The present study served a purpose of presenting a broader and more comprehensive exploration of the QoL of family caregivers of adults with IDD. This study also proposed a concise framework which was theory-driven and targeted on this special population, and the results also suggested the usefulness of this framework in terms of predicting different aspects of the family caregiver's QoL when considering multiple factors in the same time. Moreover, even though the sample size is small and under power, it will show several significant relationships between the variables and has certain extent of representativeness and implications. In addition, this study provides many insights and suggestions for the field, which will be discussed in the Implication Section in this chapter.

There are several limitations to this study. First, given time constraint and the nature of cross-sectional design, this study only provides a snapshot on the current QoL of family caregivers of adults with IDD. It is insufficient to determine any causal relationship between variables with only observational data. It therefore will be beneficial to conduct a longitudinal study in the future, to not only allow the researchers but also practitioners to gain more insight on how the maturation process affects the caregiving experiences. It will also be helpful to explore any causal relationships between selected variables to better understand the whole aspects of the issue. Having such knowledge will help design intervention or services to be more responsive to different life stages and relevant for both adults with IDD and their family caregivers.

Second, finding organizations and agencies who work with adults with IDD and their families was the first challenge for the caregivers to face. Most major IDD organizations devoted their efforts on younger population with IDD and their families, with very scarce resources focusing on adults with IDD and their families. Even if available, the information and resources were scattered and disorganized. For example, an enormous amount of emails was sent out to various organizations who serve different types of IDD across various states. However, the response rate was still extremely low so the sample size of this study is quite small. Those who were willing to take part in this study might represent a specific group of individuals. Thus, the study sample may not be truly representative of the whole population.

Third, because it was very hard to find agencies that are willing to participate, reaching out to the qualified family caregivers was even more difficult. The data collection phase lasted for seven months yet the number of participants were still not satisfying. With such a small sample size, the generalizability of the study might be limited. However, due to the natural of this population and the study design, it would not be likely to reach a larger sample size. Well-established collaborations with agencies would be needed for conducting such line of research.

Fourth, given this study aimed to evaluate various aspects of the caregivers in order to establish a comprehensive model, many psychosocial measures were selected. However, the selection of the psychosocial questionnaires and the questions of each scales might have impact on the result. For example, in order to decrease the total number of the questions, all the negative coping questions were eliminated from the Brief COPE, which could reduce the sensitivity of the measure and contribute to the insignificance relationships between Brief COPE and QoL. Additionally, due to the length of the entire questionnaire, the abbreviated versions were used instead of the full scales, or the scales have been modified. Therefore, the instruments selected for this study might not fully capture all the aspects which was intended to measure.

Finally, due to the exclusive reliance on self-reported measures, response bias could influence the validity of the outcomes. Also, the exclusive usage of online platform can also be a concern. Since having internet access and computers (or the like devices) can be an indicator of caregivers' socio-economic status or education level. Those who did not have internet access or did not belong to any agencies or listserves might have been excluded in the sample for the current study. Although the samples were from different states of the United States, the demographic information of the sample suggests that these participants were most likely to be homogeneous. For example, most of them were highly educated and had high socio-economic status) and therefore, under representative group may not be included the sample. In the future, using other channels to reach out to caregivers could be beneficial, not only to increase sample size, but also to address the heterogeneity of the group.

The Implications of the Research Findings

Implications for Researchers

While there has been much research being conducted on parents of children with IDD, little attention has been given to the long-term caregiving experiences and various outcomes for family caregivers of adults with IDD. This study can be used as a preliminary step for future researchers. Not only it provides suggestions for methodology design, the limitation of the current study can further provide directions on how to better conduct such line of research. Many hypotheses were not proved due to the small sample size of the current study. For future researchers, before making any further generalization of the study result, increasing the sample size will be the priority of the study and the recruiting process should be carefully designed before the study is carried out. It will be extremely important and helpful to build relationships with families prior to the study, which helps not only to increase the willingness for the family to join the study, but also to better understand what really matters to their lives. Also, due to the time constraint, investigations for many other variables were not conducted. Researchers should consider paying more attention to those variables in order to further determine their roles among caregivers for adults with IDD in relation to their QoL in future studies. Although other variables such as burden, were not included in this study, they might be worth researching and discussing as well. There are also plenty of literatures discussing level of burden for caregivers for individuals with disabilities (e.g., Chou et al., 2011; Raina et al., 2004). Thus, in order to develop a truly comprehensive conceptual framework to predict QoL, these variables should be carefully considered. Furthermore, based on previous research, group differences exist between caregivers for individuals with different disabilities. For example, it was more common for mothers of children with ASD to report having depressive symptoms than mothers of children with ID (Feldman et al., 2007). In the present study, the group differences were not examined since this study was designed to explore the population as a whole. In the future, it is worth evaluating the differences, if any, between various types of diagnostic groups in order to provide more tailored services to the caregivers. Different life stages should also be considered because families of individuals with IDD might experience different challenges at different stages. For example, researchers can investigate issues that families face and/or resources that are needed during various life stages (Coley, 1997). Furthermore, with a larger sample size, more complex statistical analyses can be employed, such as moderation, path analysis, or structural equation modeling, such that more results can be revealed about this unique group. Overall, this study provides support for the use of the proposed theoretical framework as a useful tool to predict caregivers' QoL. However, given the descriptive correlational nature of the study, the causality of the relationships between the predictor and outcome variables could not be verified. It is recommended the researchers to utilize longitudinal research in order to test the causal relationships among different variables.

Implications for Practitioners

Establish a comprehensive resource list is crucial not only for the researchers, but for families of individuals with IDD and for the practitioners themselves. Though the use of internet becomes universal, however, it is surprising to see how difficult it is to locate useful resources for adults with IDD online. Providing suitable services and locating resources for family caregivers will be extremely pivotal and helpful, especially when there is only a few organizations serve adults with IDD. Thus, inter-agency collaboration is highly recommended to develop a resource map for the geological areas they serve. With the complete and comprehensive resource list, it will be easier not only for the practitioners, but also families of individuals with disabilities to locate resources that they need, in order to maximize the benefits of individuals with IDD.

The study can provide a general idea of how caregivers for adults with IDD are like, and practitioners can use the study result to start investigating the needs of the caregivers. For example, the results indicates that the caregivers' depressive symptom was highly correlated with their QoL, which also mediates the relationship between behavioral issues and QoL. In addition, mental health issue is crucial in predicting family caregivers' perceived QoL. Therefore, it is recommended that practitioners take a closer look at caregiver's mental health status, especially their depressive symptoms and stress level. Educating caregivers to manage their depression and stress well will not only improve their mental health and QoL, but also improve individuals with IDD's overall QoL. Abbeduto et al. (2004) pointed out that practitioners should provide timely trainings to control individuals with IDD's behavioral issues so that caregiver's stress level can be lessened.

Additionally, with the increasing longevity for both adults with IDD and their caregivers, it means that adults with IDD will receive longer period of services, and caregivers will have to provide longer caregiving. To better serve both populations, it is a critical to understand their special needs. For instance, the present study shows that co-residence with adults with IDD would decrease caregivers' psychological related QoL. Therefore, practitioners should be careful of the mental health status of family caregivers' as well as their needs in different life stages so as to provide necessary interventions, supports, and/or useful resources in a timely manner.

Implications for Educators

When educating future rehabilitation counselors, educators should emphasize that caregiving experience is a lifelong process and the educators should take a holistic approach when educating the future counselors. Rehabilitation counselors may only see their clients for a short period of time, but the family supporting individual with IDD should also be considered and included in any intervention planning. The overall wellbeing of both the family, and the adults with IDD's, should be recognized simultaneously since they are not separable. The result shows that adults with IDD's functional limitations would affect caregivers' depressive symptom and perceived stress. Previous study also suggests that family caregivers' capacity of providing care to adults with IDD could be extended if caregivers' needs could be met, and social welfare system could be improved so that caregivers would not have to jeopardize their own physical and mental health (Seltzer et al., 2011). Most importantly, educators should include training of the full state of human development in the curriculum, and pay attention to multiple factors, such as environmental factor and support. To sum up, educators should remind future rehabilitation counselors that specific considerations are needed in order to properly support individuals with IDD and their families.

Conclusion

While most previous research focused on caregivers for children with IDD or only on some aspects of caregiver experiences, the current study presents a comprehensive exploration of the QoL of family caregivers of adults with IDD. The proposed conceptual framework was found to account for a significant amount of variance in physical related QoL, psychological related QoL, and overall QoL among family caregivers for adults with IDD. Furthermore, caring for adults with IDD who had more behavioral issues was negatively associated with caregivers' QoL. Yet, this relationship could be mediated by depressive symptoms, suggesting that caregivers' mental health is crucial to their QoL regardless higher caregiving demands. In conclusion, the findings of the present study support the predictive model of QoL for family caregivers for adults with IDD. The results of the present study can also be used to provide preliminary evidences in developing more effective, efficient, and suitable services for caregivers of adults with IDD and to better fulfilling their needs. Further research is warranted to include more factors which could also contribute to the QoL, and to further explain the complex relationships among factors affecting QoL among caregivers of adults with IDD.

APPENDICES

Appendix A – LETTER OF INVITATION TO PARTICIPATE

Dear family caregiver,

My name is Chien-chun Lin and I am a doctoral student in Rehabilitation Counselor Education in Michigan State University. I am asking you to be in a study about your own experiences as a primary family caregiver of adults with a developmental disability. I am looking for family caregivers who currently taking care of adults (age 18 or above) with developmental disabilities (IDD); identifying themselves as primary caregivers for the past 1 months; and providing care for at least 10 hours per week.

I will send out paper copy surveys to interested caregivers, web-based online survey is also available upon request. The survey takes about 40 to 60 minutes to complete, and there is a $15.00 incentive to compensate your time for participating in this study. All responses will be kept confidential and specific identifying information will be changed or left out of the final report. All written materials will be kept in a locked place, and destroyed once the report is complete.

I am conducting this study because there is little information on this topic and I would like to learn more about your caregiving experiences. This study will also help to complete the requirements for the Doctors of Philosophy in Rehabilitation Counselor Education at Michigan State University. My research advisor's name is Dr. Connie Sung. I would appreciate it if you would contact me if you are interested in participating in this study. At that time, I can answer any further questions you may have; you may also contact Dr. Sung if you have any other questions.

Thank you for your time and consideration.

Sincerely,

Appendix B – LETTER TO PROFESSIONAL COLLEAGUES

Dear __________,

My name is Chien-chun Lin and I am a doctoral student in Rehabilitation Counselor Education in Michigan State University. My doctoral dissertation consists of a study of exploring the experiences of family caregivers who are currently taking care of adult-aged family member with developmental disabilities.

I am currently recruiting participants for this study. I am looking for family caregivers who currently taking care of adults (age 18 or above) with developmental disabilities (IDD); identifying themselves as primary caregivers for the past 1 months; and providing care for at least 10 hours per week.

Participants will be expected to fill out a survey which consists of several psychological measures, it will take approximately 40 to 60 minutes to complete. I will mail out the surveys to individuals who are interested in participating in the study; a web-based online survey is also available upon request. There is a $15.00 incentive to compensate participant's time for participating in this study.

I would appreciate it if you could let me know of any family caregivers who would be interested in participating in my study. I am enclosing several fliers which describe the study. Please feel free to give them to groups with respect to race, religion, marital status, socioeconomic status and educational status.

Thank you for your time and consideration.

Sincerely,

Appendix C – CONSENT FORM

Michigan State University

Research Participant Information and Consent Form

You are cordially invited to participate in a research study about the quality of life among family caregivers of adults with intellectual and developmental disabilities (IDD). Researcher is required to provide a consent form to inform you about this project, to convey that your participation is voluntary, to explain risks and benefits of participation, and to empower you to make an informed decision. You should feel free to ask the researchers any questions you may have.

PROJECT TITLE: Quality of Life among Family Caregivers of Adults with Intellectual and Developmental Disabilities

RESEARCHER:

Dr. Connie Sung, Ph.D., CRC
Office of Rehabilitation and Disability Studies
Michigan State University
csung@msu.edu

Chien-chun Lin, MA, CRC
Rehabilitation Counselor Education,
Michigan State University
chienlin@msu.edu

DEPARTMENT AND INSTITUTION: Office of Rehabilitation and Disability Studies,
Michigan State University

1. PURPOSE OF RESEARCH:

You are cordially invited to participate in a research study exploring the quality of life among family caregivers of adults with intellectual and developmental disabilities (IDD). The purpose of this study is to understand family caregivers’ well-being in different aspects, as well as their coping strategies and social support, in terms of providing caregiving tasks to adults with IDD.

You are eligible to participate in the study if:

1. **You are a family member who is currently taking care of adults (aged 18 or above) with intellectual and developmental disabilities (IDD); and**
2. **You identify yourself as the primary caregiver for the past one month; and**
3. **You provide care for at least 10 hours per week.**

2. WHAT YOU WILL DO:

If you decide to participate, all that will be required of you is to complete the survey. The survey consists of a series of nine self-report questionnaires, which will take about 40-60 minutes. You can also request to fill out the survey on a secured website by contacting the researcher.

3. POTENTIAL BENEFITS:

Your participation in this study may generate data useful for better understanding the caregiving experiences and perspectives among family caregivers of adults with IDD. Further, it is anticipated that the findings from this study have the potential to enhance and inform different interventions which focus on different age groups of the caregivers and the care recipients. Thus, your participation will contribute to helping both the family caregivers and adults with IDD to have more tailored services and improve their quality of life.

4. POTENTIAL RISKS:

We do not anticipate any risks to you through your participation in this study.

5. PRIVACY AND ANONYMITY:

All information gathered in this study will be used only for research purposes and be accessible only by the research personnel affiliated with this project. All data for this project will be kept strictly anonymous. No names or identifiers will be revealed for non-research purposes. The researchers will not be able to connect your name with your response. The results of this study may be published or presented at professional meetings, but the identities of all research participants will remain anonymous. All research materials will be stored in a locked file cabinet and/or password protected computer.

If you choose to participate, your responses will be completely anonymous. When the survey is successfully completed, you will have the option to leave your name, and email/ mailing address to receive a $10 gift card; but this information is separate from the responses you will provide in the survey, so your answers will still remain anonymous. Your name and email/mailing address will only be used for sending you the gift card and they will be deleted after the gift card is sent. The dataset will be managed and used only by the researchers related to this study. Only group information and aggregated results will be included in any publications or presentation from the study.

6. YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAWAL:

I very much hope that you will participate in the study and respond to all items, however, participation is completely voluntary. You have the right to say no. You may change your mind at any time and withdraw. You may choose not to answer specific questions or to stop participating at any time. There are no consequences of withdrawal or incomplete participation.

7. COSTS AND COMPENSATION FOR BEING IN THE STUDY:

There are no costs to you to participate in this study other than the value you place on your time. Upon completion of the survey, you will receive a $10 gift card within one month for participating in this study. You will have an option to sign up for the gift card. **If you choose to, you will fill out the attached reply slip and mail it back along with the completed questionnaire indicating that you would like a gift card, and provide your name, email/mailing address and method of receipt. Please note that your name and email/mailing**

address will be obtained separately from your responses to the questionnaire and it will be deleted after the gift card is sent.

8. CONTACT INFORMATION FOR QUESTIONS AND CONCERNS:

You may ask any questions about the research at any time. If you have any questions about this study, such as scientific issues, how to do any part of it, or prefer an alternative method for taking this survey (e.g., by using the secure website or by phone) please contact the principal investigator, Dr. Connie Sung at (517) 353-1638 or csung@msu.edu, or Chien-chun Lin at 517-944-5594, or chienlin@msu.edu, or regular mail at: Michigan State University, 620 Farm Lane, Room 460, East Lansing, MI 48824.

If you have any questions about your role and rights as a research participant, would like to obtain information or offer input, or would like to register a complaint about this study, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Programs at 517-355-2180, Fax 517-432-4503, or email: irb@msu.edu, or regular mail at: 207 Olds Hall, MSU, East Lansing, MI 48824.

9. DOCUMENTATION OF INFORMED CONSENT:

Again, your participation is completely voluntary and anonymous. You are free to refuse to participate in this research project or to withdraw your consent and discontinue participation in the project at any time without penalty or loss of benefits to which you are otherwise entitled. Your participation will not affect your relationship with the institution(s) involved in this project.

MY RETURN OF THIS SURVEY IMPLIES MY CONSENT TO PARTICIPATE IN THIS RESEARCH AND I HAVE BEEN GIVEN A SECOND COPY OF THIS FORM TO KEEP FOR MY RECORDS.

Appendix D – DEMOGRAPHIC QUESTIONNAIRE

Part A:

Please check or fill in the blanks as best descriptions of your situations

1.	Age:	
2.	Gender:	☐ Male ☐ Female ☐ Transgender ☐ Prefer not to answer
3.	Race/Ethnicity: (check all that apply)	☐ Caucasian (White) ☐ African American ☐ Hispanic/Latino ☐ Asian & Pacific Islanders ☐ Native/Indian American ☐ Others (please specify): __________________________________ ☐ Prefer not to answer
4.	Marital Status:	☐ Married ☐ Single ☐ Separated ☐ Divorced ☐ Widowed ☐ Partner/ Significant other ☐ Cohabitated ☐ Prefer not to answer
5.	Employment Status:	☐ Full-time employment (35 hours or more per week) ☐ Part-time employment (1 to 34 hours per week) ☐Not employed ☐ Retired
6.	Highest education you have completed:	☐ Some high school, no diploma ☐ GED ☐ High school diploma ☐ Some college ☐Associate degree ☐ Bachelor's degree ☐ Some graduate level classes ☐ Master's degree ☐ Ph.D. degree

		☐ Other (Please specify:__________________)
7.	Your annual household income:	☐Below $20,000 ☐ $20,000- $30,000 ☐ $30,000- $40,000 ☐ $40,000-$50,000 ☐ $50,000-$60,000 ☐ $60,000-$70,000 ☐ $70,000 and above ☐ Prefer not to answer
8.	Do you have any health conditions?	☐ Yes (Please answer Q91) ☐ No ☐ Prefer not to answer
9.	If yes, are your health conditions related to physical or mental issues? (check all that apply)	☐ Visual impairment ☐ Hearing impairment ☐ Arthritis ☐ Heart problems ☐ High blood pressure ☐ Obesity ☐ Chronic obstructive pulmonary disease (COPD) ☐ Diabetes ☐ Mild cognitive impairment ☐ Depression ☐ Anxiety ☐ Psychosis ☐ Back pain ☐ Other (Please specify:__________________) ☐ Prefer not to answer
10.	How long have you had the condition?	☐ Less than 1 year ☐ 2 ~ 5 years ☐ Over 5 years ☐ Prefer not to answer
11.	Relationship to the person (s) with IDD:	☐ Parent ☐ Spouse ☐ Sibling ☐ Relatives ☐ Other relatives(Please specify:__________________)
12.	Total number of years have been identifying as a primary	

	caregiver of the person(s) with IDD:	
Part B: Please check or fill in the blanks as best descriptions of the family member with IDD		
13.	Age of the family member with developmental disabilities (IDD):	
14.	What is the category of the developmental disability diagnosis? Check all that apply.	Primary Diagnosis: ☐ Autism Spectrum Disorder ☐ Intellectual Disability ☐ Down Syndrome ☐ Traumatic Brain Injury ☐ Others (please specify):______________________ Secondary Diagnosis: ☐ Autism Spectrum Disorder ☐ Intellectual Disability ☐ Down Syndrome ☐ Traumatic Brain Injury ☐ Others (please specify):______________________
15.	Is the person with IDD currently employed?	☐ Yes, full-time employed. (35 or more hours per week) ☐ Yes, part-time employed. (1-34 hours per week) ☐ No, still in school ☐ Not employed and not in school
16.	Relationship to the person (s) with IDD:	☐ Parent ☐ Spouse ☐ Sibling ☐ Relatives ☐ Others (Please specify:__________________)
17.	Total number of years have been identifying as a primary caregiver of the person(s) with IDD:	
18.	In the past year, average number of hours (per week) providing care to the person(s) with IDD:	
19.	Does the person with IDD live with you?	☐ Yes ☐ No (Please answer Q20)

20.	Living arrangement of the person with IDD:	☐ Lives with parents ☐ Lives with other family members ☐ Lives in a group home ☐ Lives independently with daily assistance ☐ Lives independently without assistance ☐ Homeless
21.	Have you ever utilized respite care services?	☐ Yes, I am currently using respite care services ☐ Yes, but only in the past. ☐ No, but I am considering ☐ No, I don't need to use respite care service ☐ No, respite care services is not available for my family
21.	What benefits does the person with IDD receive? Check all that apply.	☐ SSI ☐ SSDI ☐ Other (please specify): ____
22.	What insurance does the person with IDD have? Check all that apply.	☐ Medicaid ☐ Medicare ☐ Private insurance through family member(s) ☐ Private insurance through employer ☐ Not covered under any insurance ☐ Other (please specify):________________________________

Appendix E – PSYCHOSOCIAL QUESTIONNAIRES

Waisman Activities of Daily Living Scale (W-ADL)

INSTRUCTIONS: We would like to know about your family member with IDD's current level of independence in performing activities of daily living. For each activity please tell me the number which best describes your son/daughter's ability to do the task. For example, Independent would mean your son/daughter is able to do the task without any help or assistance"

PLEASE RATE (name of person)'S LEVEL OF INDEPENDENCE IN…		**ABILITY TO PERFORM TASK** **2 = Independent or does on own** **1 = does with help** **0 = does not do at all**		
1.	Making his/her own bed	**2**	**1**	**0**
2.	Doing household tasks, including picking up around the house, putting things away, light housecleaning, etc.	**2**	**1**	**0**
3.	Doing errands, including shopping in stores	**2**	**1**	**0**
4.	Doing home repairs, including simple repairs around the house, non-technical in nature; for example, changing light bulbs or repairing a loose screw	**2**	**1**	**0**
5.	Doing laundry, washing and drying	**2**	**1**	**0**
6.	Washing/bathing	**2**	**1**	**0**
7.	Grooming, brushing teeth, combing and/or brushing hair	**2**	**1**	**0**
8.	Dressing and undressing	**2**	**1**	**0**
9.	Toileting	**2**	**1**	**0**

10.	Preparing simple foods requiring no mixing or cooking, including sandwiches, cold cereal, etc.	**2**	**1**	**0**
11.	Mixing and cooking simple foods, fry eggs, make pancakes, heat food in microwave, etc.	**2**	**1**	**0**
12.	Preparing complete meal	**2**	**1**	**0**
13.	Setting and clearing table	**2**	**1**	**0**
14.	Drinking from a cup	**2**	**1**	**0**
15.	Eating from a plate	**2**	**1**	**0**
16.	Washing dishes (including using a dishwasher)	**2**	**1**	**0**
17.	Banking and managing daily finances, including keeping track of cash, checking account, paying bills, etc. (Note: if he/she can do a portion but not all circle '1' with help.)	**2**	**1**	**0**

Behavioral Scale

INSTRUCTIONS:

This questionnaire is about adults with an intellectual or developmental disability. It is about the kind of behaviors and difficulties that may be faced by adults as they become older and by those who care for them. It should be completed by someone who knows the person well and who has been working with him or her during the past two weeks (such as a parent, worker or other caregiver).

		How often Rate how often the behavior has occurred during the past two weeks **0**= Has not occurred in the past two weeks **1**= Once in the past two weeks **2**= 2-3 times in the past two weeks **3**= More than 2-3 times in the past two weeks **4**= Once a day **5**= More than once a day **6**= Once an hour/all the time	**Management difficulty** Rate how much of a management difficulty the behavior was **0**= No difficulty **1**= Very little difficulty **2**= Mild difficulty **3**= Moderate difficulty **4**= Moderate—severe difficulty **5**= Severe difficulty **6**= Extremely severe difficulty
1.	**Was restless** Paced up and down, was unable to sit still, fidgeted.	**0 1 2 3 4 5 6**	**0 1 2 3 4 5 6**
2.	**Was vocally disruptive** Was vocal for no apparent reason (e.g. moaned, shouted, screamed, called out).	**0 1 2 3 4 5 6**	**0 1 2 3 4 5 6**
3.	**Took something belonging to someone else** Took money or objects, went through other people's possessions (e.g. bags/ coats/ bedrooms).	**0 1 2 3 4 5 6**	**0 1 2 3 4 5 6**
4.	**Was uncooperative** Was unwilling to carry out or be supported with a daily task (e.g. bathing, dressing, brushing teeth), or comply with care requests (e.g.	**0 1 2 3 4 5 6**	**0 1 2 3 4 5 6**

	refused to go to bed, to eat or drink).		
5.	**Was aggressive towards others verbally or through gestures** Expressed aggression towards others verbally or by using signs/ gestures (e.g. shouted, name called, threatened, swore).	**0 1 2 3 4 5 6**	**0 1 2 3 4 5 6**
6.	**Was aggressive toward other physically** Attempted to/was actually physically aggressive towards another person (e.g. kicked, hit, spat, scratched, bit, pushed, grabbed).	**0 1 2 3 4 5 6**	**0 1 2 3 4 5 6**
7.	**Displayed sexually inappropriate behavior** Made an inappropriate sexual advance/gesture, made sexual references, non-accidentally exposed self.	**0 1 2 3 4 5 6**	**0 1 2 3 4 5 6**
8.	**Was inactive** Was not engaged in any activity, was inattentive	**0 1 2 3 4 5 6**	**0 1 2 3 4 5 6**
9.	**Experienced difficulty concentrating** Became easily distracted, very agitated	**0 1 2 3 4 5 6**	**0 1 2 3 4 5 6**

Patient Health Questionnaire (PHQ-9)

INSTRUCTIONS:

Over the last two weeks, how often have you been bothered by any of the following problems?

	Not at all	Several days	More than half of the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless.	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much.	0	1	2	3
4. Feeling tired or having little energy.	0	1	2	3
5. Poor appetite or overeating.	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down.	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television.	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual.	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself.	0	1	2	3

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- ☐ Extremely difficult
- ☐ Very difficult
- ☐ Somewhat difficult
- ☐ Not difficult at all

Perceived Stress Scale (PSS)

INSTRUCTIONS:

The questions in this scale ask you about your feelings and thoughts during the **LAST MONTH**. In each case, please indicate with a check how often you felt or thought a certain way.

	Never	Almost never	Sometimes	Fairly often	Very often
1. In the last month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2. In the last month, how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
3. In the last month, how often have you felt nervous and "stressed"?	0	1	2	3	4
4. In the last month, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
5. In the last month, how often have you felt that things were going your way?	0	1	2	3	4
6. In the last month, how often have you found that you could not cope with all the things that you had to do?	0	1	2	3	4
7. In the last month, how often have you been able to control irritations in your life?	0	1	2	3	4
8. In the last month, how often have you felt that you were on top of things?	0	1	2	3	4
9. In the last month, how often have you been angered because of things	0	1	2	3	4

that happened that were outside of your control?					
	Never	Almost never	Sometimes	Fairly often	Very often
10. In the last month, how often have you felt difficulties pilling up so high that you could not overcome them?	0	1	2	3	4

Brief COPE

INSTRUCTIONS:

These items deal with ways you've been coping with the stress in your life since you have to provide care to your family member has an IDD. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

		I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1.	I've been concentrating my efforts on doing something about the situation I'm in.	**1**	**2**	**3**	**4**
2.	I've been getting emotional support from others.	**1**	**2**	**3**	**4**
3.	I've been taking action to try to make the situation better.	**1**	**2**	**3**	**4**
4.	I've been getting help and advice from other people.	**1**	**2**	**3**	**4**
5.	I've been trying to see it in a different light, to make it seem more positive.	**1**	**2**	**3**	**4**
6.	I've been trying to come up with a strategy about what to do.	**1**	**2**	**3**	**4**
7.	I've been getting comfort and understanding from someone.	**1**	**2**	**3**	**4**
8.	I've been looking for something good in what is happening.	**1**	**2**	**3**	**4**

9.	I've been making jokes about it.	**1**	**2**	**3**	**4**
10.	I've been accepting the reality of the fact that it has happened.	**1**	**2**	**3**	**4**
11.	I've been trying to find comfort in my religion or spiritual beliefs.	**1**	**2**	**3**	**4**
12.	I’ve been trying to get advice or help from other people about what to do.	**1**	**2**	**3**	**4**
13.	I've been learning to live with it.	**1**	**2**	**3**	**4**
14.	I've been thinking hard about what steps to take.	**1**	**2**	**3**	**4**
15.	I've been praying or meditating.	**1**	**2**	**3**	**4**
16.	I've been making fun of the situation.	**1**	**2**	**3**	**4**

Interpersonal Support Evaluation List (ISEL)

INSTRUCTIONS:

This scale is made up of a list of statements each of which may or may not be true about you. For each statement circle "definitely true" if you are sure it is true about you and "probably true" if you think it is true but are not absolutely certain. Similarly, you should circle "definitely false" if you are sure the statement is false and "probably false" if you think it is false but are not absolutely certain.

	Definitely False	Probably False	Probably True	Definitely True
1. If I wanted to go on a trip for a day (for example, to the country or mountains), I would have a hard time finding someone to go with me.	1	2	3	4
2. I feel that there is no one I can share my most private worries and fears with.	1	2	3	4
3. If I were sick, I could easily find someone to help me with my daily chores.	1	2	3	4
4. There is someone I can turn to for advice about handling problems with my family.	1	2	3	4
5. If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me.	1	2	3	4
6. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.	1	2	3	4
7. I don't often get invited to do things with others.	1	2	3	4
8. If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc.).	1	2	3	4
9. If I wanted to have lunch with someone, I could easily find someone to join me.	1	2	3	4
10. If I was stranded 10 miles from home, there is someone I could call who could come and get me.	1	2	3	4
11. If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it.	1	2	3	4

12. If I needed some help in moving to a new house or apartment, I would have a hard time finding someone to help me.	1	2	3	4

WHOQOL-BREF

INSTRUCTIONS:

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither poor nor good	Good	Very good
1. How would you rate your quality of life?	1	2	3	4	5
2. How satisfied are you with your health?	1	2	3	4	5

The following questions ask about <u>how much</u> you have experienced certain things in the last two weeks.

	Not at all	A little	A moderate amount	Very much	An extreme amount
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4. How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5. How much do you enjoy life?	1	2	3	4	5
6. To what extent do you feel your life to be meaningful?	1	2	3	4	5
	Not at all	A little	A moderate amount	Very much	Extremely
7. How well are you able to concentrate?	1	2	3	4	5
8. How safe do you feel in your daily life?	1	2	3	4	5
9. How healthy is your physical environment?	1	2	3	4	5

The following questions ask about <u>how completely</u> you experience or were able to do certain things in the last two weeks.

	Not at all	A little	Moderately	Mostly	Completely
10. Do you have enough energy for everyday life?	1	2	3	4	5
11. Are you able to accept your bodily appearance?	1	2	3	4	5
12. Do you have enough money to meet your needs?	1	2	3	4	5
13. How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14. To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
	Very poor	Poor	Neither poor nor good	Good	Very good
15. How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how <u>good or satisfied</u> you have felt about various aspects of your life over the last two weeks.

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16. How satisfied are you with your sleep?	1	2	3	4	5
17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18. How satisfied are you with your capacity for work?	1	2	3	4	5
19. How satisfied are you with yourself?	1	2	3	4	5
20. How satisfied are you with your personal relationships?	1	2	3	4	5
21. How satisfied are you with your sex life?	1	2	3	4	5

22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
24. How satisfied are you with your access to health services?	1	2	3	4	5
25. How satisfied are you with your transport?	1	2	3	4	5

The following question refers to <u>how often</u> you have felt or experienced certain things in the last two weeks.

	Never	Seldom	Quite often	Very often	Always
26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

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