

Predicting Quality of Life among Family Caregivers of Adults with Intellectual and/or Developmental Disabilities

Prédire la qualité de vie des familles qui s'occupent d'adultes ayant une déficience intellectuelle et/ou un trouble du développement

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Abstract

The current study used a proposed conceptual framework to investigate how various physical, psychosocial, and health factors of adults with intellectual and/or developmental disabilities (I/DD) affect family caregivers' perceived quality of life (QoL) in the caregiving process. The 124-item survey for this study consisted of several psychological measures and a demographic questionnaire. A total of 88 valid responses were analyzed by correlational analysis, hierarchical regression analysis, and mediation analysis. Results indicated that caring for adults with I/DD significantly affected family caregivers' QoL. Caring for adults with I/DD who presented with substantial behavioural issues was negatively associated with caregivers' QoL. This negative relationship was mediated by depression symptoms, suggesting that caregivers' mental health is crucial to their QoL, aside from higher caregiving demands. The results of this study provide a more comprehensive exploration of the QoL of family caregivers of adults with I/DD than previously existed in the literature and might be used to provide further suggestions to the researchers and practitioners about caregivers' unique needs. For example, timely education on managing caregivers' depressive

symptoms and stress to improve both caregivers' own QoL and the care recipients' overall QoL, ultimately might extend the capacity of caregivers to continue providing care without jeopardizing their physical health, mental status, and overall QoL.

Résumé

La présente étude s'est appuyée sur un cadre conceptuel pour investiguer comment divers facteurs physiques, psychosociaux et de santé chez les adultes ayant une déficience intellectuelle (DI) ou un trouble du développement (TD) affectent la perception de la qualité de vie (QdV) de aidants naturels dans le processus de soin. Le questionnaire de 124 items pour cette étude consistait en plusieurs mesures psychologiques ainsi qu'un questionnaire démographique. Un total de 88 réponses valides a été analysé selon des analyses corrélationnelles, de régression hiérarchique et de médiation. Les résultats indiquent que s'occuper d'adultes ayant une DI ou un TD a affecté la QdV des proches aidants de façon significative. S'occuper d'adultes ayant une DI ou un TD présentant des comportements problématiques importants était négativement associée à la QdV des aidants. Cette relation négative était médiée par les symptômes de la dépression, ce qui suggère que la santé mentale des aidants est cruciale à leur QdV, outre les exigences liées aux soins. Les résultats de cette étude fournissent une exploration plus exhaustive de la QdV des proches aidants d'adultes ayant une DI ou un TD que celle qui existait auparavant dans les écrits scientifiques et pourraient être utilisés pour fournir d'autres suggestions aux chercheurs et aux praticiens concernant les besoins uniques des aidants naturels. Par exemple, une éducation en temps opportun sur la gestion des symptômes de la dépression et du stress des aidants afin d'améliorer à la fois leur propre QdV et la QdV globale des bénéficiaires de soins, pourrait en fin de compte augmenter la capacité des aidants à continuer à fournir des soins sans compromettre leur santé physique et mentale ainsi que leur QdV globale.

Mots-clés : Qualité de vie, aidant naturel, déficience intellectuelle, trouble du développement

Introduction

According to the Centers for Disease Control and Prevention (CDC), one in six children in the United States (15% of children 3–17 years of age) were diagnosed with one or more intellectual and or developmental disabilities (I/DD), such as autism spectrum disorder, cerebral palsy, intellectual disability (ID), Down syndrome, Rett syndrome, epilepsy, and other developmental delay conditions during 2009-2017 (CDC, 2021; Zablotsky et al., 2019). Caregivers of children with I/DD an often report higher stress, depression, and physical and or mental issues, and lower perceived quality of life (QoL), support, financial capacity, and socioeconomic status (e.g., Abbeduto et al., 2004; Allik et al., 2006; Brown et al., 2003; Emerson, 2003; Mugno et al., 2007).

The 2017 U.S. Census report indicates that the number of people 65 years or older was 15% of the entire population in 2016 and may rise to almost 23% by 2060 (U.S. Census Bureau, 2017). People with I/DD also live longer, owing to medical advances and improved living conditions. The average age of death ranges from the mid-50s to the early 70s, depending on the severity and type of disability (Heller & Arnold, 2010). Although a plethora of studies have focused on the QoL of caregivers of children with I/DD, much less attention has been paid to family caregivers of adults with I/DD. Thus, the primary purpose of this study was to investigate the overall QoL of aging family caregivers of adults with I/DD, and how various physical, psychosocial, and health

factors affect their perceived QoL, by using a proposed conceptual framework (details described below).

Past studies have indicated that most adults with I/DD live with their parents even into adulthood and often stay until their parents either become incapable of caring for them or pass away (Essex et al., 1999; Fujiura, 1998; Hayden & Heller, 1997). Fujiura (1998) has estimated that 60% of people with I/DD continue to live with their parents in adulthood. Seltzer et al. (2011) have also reported that 39% of adults with I/DD in their study continued to live with their parents when their parents were in their 60s. As the prevalence of I/DD continues to rise, more people with I/DD may continue to reside with their parents even longer. When their adult children with I/DD move out, aging parents tend to remain involved and maintain part of their caregiving (Ben-Zur et al., 2005; Essex et al., 1999; Krauss et al., 2005; Raina et al., 2004).

Given that both caregivers and people with I/DD have longer life expectancies than in the past, parents of adults with I/DD are expected to provide care for extended periods. Simultaneously, these family caregivers are also likely to need to complete tasks outside parenting (such as employment), pursue their interests (Yoong & Koritsas, 2012), and address their own declining health conditions (Boerner & Reinhardt, 2003). Researchers have found that aging caregivers show significantly more depressive symptoms and poorer health related QoL when they co-reside with adult children with I/DD for longer periods (Seltzer et al., 2004). These findings indicate that long-term co-residence significantly affects caregivers' well-being. Therefore, understanding the caregivers' perspective, including their needs, and how providing around-the-clock caregiving tasks affects their perceived QoL, is crucial.

Conceptual Framework

To better understand which factors predict a family caregiver's perceived level of QoL, a conceptual framework must be created. As Raina et al. (2004) have indicated, a well-structured conceptual framework is required to understand the complex nature between the direct and indirect relationships affecting the health and well-being of family caregivers.

Three existing conceptual frameworks were considered for their features to develop a suitable framework: (1) Blacher's (2001) conceptual framework, which investigates the transition to adulthood of young adults with I/DD; (2) Armstrong, Birnie-Lefcovitch, and Ungar's (2005) framework, which describes the pathways between the well-being of families of children with emotional issues and social support, and how environmental stressors affect family well-being; and (3) Raina et al.'s (2004) conceptual model, which explores relationships between multiple variables and psychological and physical health as the outcomes.

In examining the QoL among family caregivers, several factors were borrowed from these existing models because they are supported by the literature as possible predictors. For example, in Blacher's (2001) framework, the well-being of families of children with IDs can be predicted by several factors, such as family resources, individual characteristics, and life events. This model focuses on the effects of transition on family well-being, and Blacher (2001) has indicated that QoL can be viewed as a summary of whether the child with ID has a successful transition outcome. Armstrong et al.'s (2005) model was reviewed because it includes factors potentially affecting family function, and the definition of well-being in this model is similar to the definition of QoL from the World Health Organization (WHO); in addition, parental emotional well-being is a proximal outcome of this model. Social support from Armstrong et al.'s (2005)

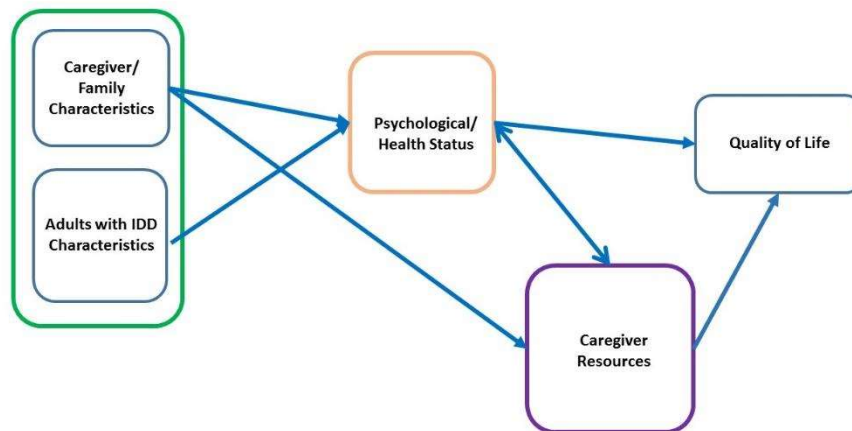
model was also included in the new proposed conceptual framework because past literature (e.g., Ben-Zur et al., 2005; Feldman et al., 2007; Heller et al., 2007) has indicated that social support is a coping skill for parents under high stress. In Armstrong et al.'s (2005) model, social support is viewed as a mediator between environmental and personal stressors and characteristics. Finally, Raina et al.'s (2004) framework targets parents of children with developmental disabilities, particularly children with cerebral palsy. Multiple dimensions are required to better conceptualize the complex direct or indirect pathways among factors during the caregiving process. This comprehensive model has two major outcomes—the psychological health and physical health of the caregivers—which according to Raina and colleagues (2004) are strongly correlated with the child's conditions and may also provide insight into preventive strategies.

The three conceptual frameworks mentioned above have provided substantial information on the complexity of exploring caregiver well-being and adjustment to the child's disabilities. However, none of the models described above focus on the caregivers of adults with I/DD. Herein, the three conceptual frameworks have been modified and combined, and a new framework is proposed to better answer the specific research questions of this present study.

The present conceptual framework is similar to Raina et al.'s (2004) model, which is the most comprehensive and multidimensional model among the three prior conceptual models. Because the target population of the present study is caregivers of adults with I/DD, the levels of functional independence and behavioural issues of adults with I/DD were added to the model. Having a family member with a disability is not the only factor affecting caregivers, because the overall effects of aging on caregiver health condition should also be considered, particularly in the target population for the study. Moreover, health status was considered in the context of exploring aging caregiver QoL. Another stressor is caregiving demands, which relate to the type of disability, the functional independence level, and the behavioural issues of adults with I/DD. For example, maladaptive behaviours in children with ASD are significantly associated with parental stress and coping (Abbeduto et al., 2004; Feldman et al., 2007). Higgins et al. (2005) have also indicated that the severe behavioural problems and ongoing dependency of children with ASD, and the limits imposed on family activities, strongly affect the ability of families to function effectively. The demands of time and energy in caring for people with disabilities have been identified as one of the most stressful factors.

Social support and coping strategies are both included as caregiver resources in the proposed model because they are both recognized as predictors of the QoL of caregivers of people with disabilities. The original outcomes of Raina et al.'s (2004) model were physical and psychological well-being. We believe that physical and psychological well-being are only part of the entire picture in the present conceptual framework. Additionally, past research has tended to focus on related aspects, such as health or psychological well-being, rather than overall QoL (Yoong & Koritsas, 2012). Therefore, in the present study, the variable called QoL included not only psychological, and health aspects of the caregiver QoL, but also aspects of material well-being (such as finance, possessions, or living environment), social well-being (such as interpersonal relationships), and development and activity well-being (such as using one's skills to accomplish various activities including education, work, or leisure activities) as proposed by Felce and Perry (1995).

Figure 1
Proposed Conceptual Framework



The arrows in the proposed framework (Figure 1) represent relationships between variables identified and evidenced in the literature. This proposed framework tests three hypotheses: (1) Demographic variables, psychological/health factors, and caregiver resources, are associated with the QoL of family caregivers of adults with I/DD; (2) The modified conceptual framework will account for a significant amount of variance in the QoL of family caregivers of adults with I/DD; and (3) Having less depressed, less stressed mental health status would improve family caregiver QoL even among caregivers of adults with I/DD who show more behavioural issues.

As already mentioned, the measures used in this study were intended to provide a comprehensive picture of caregiver QoL. In this modified model, caregiver QoL was examined from a number of different perspectives. The results of the present study should aid in establishing responsive services and support for aging family caregivers so that they can continue to provide care without sabotaging their own physical and psychological well-being and their overall QoL. The information obtained from this study should be critical to service providers in designing and developing effective services not only for adults with I/DD but also for their caregivers.

Materials and Methods

Participants

The inclusion criteria for this study were as follows: (1) family members caring for adults (aged 18 years or older) with I/DD, (2) those who identified themselves as the primary caregivers in the past month, and (3) those who provided care for at least 10 hours per week. A total of 88 valid responses were obtained from different parts of the United States, and one was obtained from the United Kingdom. Most participants identified themselves as white (87.5%), married (67.1%) women who had been the primary caregivers of adults with I/DD for 10–30 years. The age ranged from 30 to above 60, and the majority were between 50–59 years of age (mean = 53.9). More than 90% of the caregivers resided with the adults with I/DD at the time of the study. Additionally, 44.3% of the caregivers reported having at least one health condition in the past year.

Measures

Most study participants completed a survey via an online survey platform (Qualtrics), with one participant returning a hard copy questionnaire. This 124-item survey consisted of several different instruments (Table 1) representing different parts of the conceptual framework and QoL as the outcome of interest. In the text below we provide some detail about each category of variables in the survey.

Table 1

List of Instruments in the 124-item Survey

Variables	# of Items	Instrument	Cronbach's Alpha*
Demographic Information	21 items	Demographic Questionnaire	
Functional Independence Level	17 items	Waisman Activities of Daily Living Scale (W-ADL)	.95
Behavioural Issues	9 items	Extracted from: Assessment for Adults with Developmental Disabilities (AADS)	.94
Psychological Factors	9 items	Patient Health Questionnaire (PHQ-9)	.89
	14 items	Perceived Stress Scale (PSS)	.58
Coping strategies	16 items	Extracted from: BRIEF-COPE	.88
Social Support	12 items	Interpersonal Support Evaluation List-12 (ISEL-12)	.89
Quality of Life	26 items	WHOQOL-BREF	Physical-related QoL: .80 Psychological-related QoL: .87
Total number of items	124 items		

Note. *, the values of Cronbach's alpha are those for the study sample. A copy of the survey and permissions to use the instruments are available from the authors upon request.

Demographic Information

The demographic variables collected for the caregivers of adults with I/DD in the present study included age, race/ethnicity, gender, 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 according to previous research. The following demographic information on the care recipients with I/DD was collected: age, diagnosis, residential status (e.g., with family, independent living, or group home), employment status (full time, part-time, volunteer, or still in school), and Social Security Administration (SSA) beneficiary status (e.g.,

Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI), Medicaid and/or Medicare).

Functional and Independence Level

The care recipient's functional independence level was assessed with the Waisman Activities of Daily Living Scale (Maenner et al., 2013). The W-ADL scale was developed by Maenner et al. (2013) specifically for adolescents and adults with I/DD to systematically assess their activity limitations, and it has been validated to have acceptable psychometric properties. The W-ADL's target population fits well with the present study. It uses a 3-point Likert scale (2 = independent or does on own; 1 = does with help; 0 = does not do at all), with higher scores indicating a higher functional independence level. The internal consistency for this measure in the present study was good (Cronbach's alpha = .95). One sample question in the scale is "Rate participant's level of independence in making his/her own food."

Behavioural Issues

Behavioural issues were evaluated with several questions extracted from the Assessment for Adults with Developmental Disabilities (AADS; Kalsy et al., 2002). The AADS scale was developed by Kalsy and colleagues (2002) for adults with developmental/learning disabilities to evaluate dementia-related behaviours that may be experienced with aging. This scale is an informant-based questionnaire with two subscales: behavioural excess (11 items) and behavioural deficits (17 items), which are commonly associated with dementia (Kalsy et al., 2002). However, because the present study aimed to investigate only the behavioural issues of people with I/DD, some dementia-related items were not appropriate for this study. Thus, nine items representing behavioural issues were selected as an abbreviated AADS in the current research for caregivers to rate the care recipients' behavioural issues. The caregivers provided ratings on a 7-point Likert scale in terms of frequency; for example, one question asks whether the care recipient was aggressive toward others, verbally or through gestures, and the study participant rated the response from 0 to 6 on this scale (from 0 = "has not occurred in the past two weeks" to 6 = "once an hour/all the time") and the management difficulty (from 0 = "no difficulty" to 6 = "extremely severe difficulty").

Psychological Factors

Patient Health Questionnaire (PHQ-9). The PHQ-9, developed by Kroenke and Spitzer (Kroenke & Spitzer, 2002), is a depression screening tool that includes DSM-IV depression diagnostic criteria and other major depressive symptoms. It contains nine items (representing depressive symptom criteria) and can be completed in a short amount of time. The respondents answer each question reflecting how often they have been bothered by specific scenarios over the past 2 weeks on a 4-point Likert scale (from 0 = "not at all" to 3 = "nearly every day"), thus providing a 0 = 27 total severity score. For example, study participants were asked to rate whether they have had little interest or pleasure in doing things in the past 2 weeks.

At the end of the nine questions, the questionnaire also asked the participants to rate how difficult maintaining their everyday life has been (e.g., working, doing chores, or interacting with others). This 10th question indicates the extent to which depressive symptoms affect the level of function. This question provided additional information in the present study but was not used for scoring purposes. A higher score indicates more severe depressive symptoms. The psychometric properties of the PHQ-9 have often been examined among different populations. The internal consistency reliability (Cronbach's alpha) ranged from .84 to .89, on the basis of different sample populations, and the criterion and construct validity were also well established, as compared with other existing measures in the field (Kroenke et al., 2001). The present study sample was also found to have good internal consistency (Cronbach's alpha = .89).

Perceived Stress Scale (PSS). The PSS, developed by Cohen and colleagues (1983), is a self-administered questionnaire with only 14 items: seven positive and seven negative. It was used to measure family caregivers' perceived stress in the present study. The scale was designed to explore how unpredictable, uncontrollable, and overloaded respondents find their lives (Cohen & Williamson, 1988). The questionnaire asked respondents to rate the frequency of their feelings and thoughts during the past month (for example, in the past month, how often have you felt nervous and stressed?) on a 5-point Likert scale (from 0 = "never" to 4 = "often"), with higher scores suggesting a higher level of chronic stress.

The psychometric properties of the PSS have been examined across various studies. Lee (2012) has reviewed all the studies and concluded that the PSS has good psychometric properties across studies. Both the internal consistency reliability (Cronbach's alpha) and the test-retest reliability were above .70. In the present study, PSS had a questionable internal consistency for the study sample (Cronbach's alpha = .58).

Coping Strategies

The Brief COPE inventory was used to examine the family caregivers' coping strategies in difficult situations and to compare different coping strategies among family caregivers in the present study. The original COPE inventory was developed by Carver et al. (1989) to assess the different ways in which people respond to stressful situations. Owing to the length and the redundancy of the full version (60 questions), Carver (1997) then reduced the full version to a brief scale containing 28 questions. A total of 14 subscales are included in the Brief COPE inventory; it uses a 4-point Likert scale (from 1 = "I haven't been doing this at all" to 4 = "I've been doing this a lot"). For example, study participants would answer indicate whether they "have been getting help and advice from other people."

The Brief COPE has been found to have acceptable psychometric properties, such as internal consistency (Cronbach's alpha) ranging from .50 to .90 for each abbreviated subscale. Although each subscale has only two items, the reliability meets the minimum requirement of .50 (Carver, 1997). In this study, only eight positive coping skills (16 questions) were included in the questionnaire. The present study sample was also found to have good internal consistency (Cronbach's alpha = .88).

Social Support

The caregiver's social support was measured by the Interpersonal Support Evaluation List-12 (ISEL), developed by Cohen and his colleagues (1985). The abbreviated scale was chosen to measure perceptions of social support among aging caregivers in the present study. The abbreviated ISEL has 12 items based on three domains: (1) appraisal support, (2) belonging support, and (3) tangible support. Each subscale has four items, each of which is rated by participants on a 4-point Likert scale (1 = "definitely false" to 4 = "definitely true"). For example, study participants would indicate whether they "don't often get invited to do things with others." Higher scores reflect greater perceived availability of support resources.

The abbreviated ISEL has been demonstrated to have adequate test-retest and internal consistency reliability. The internal consistency reliability (Cronbach's alpha) of the general population ranged from .81 to .91; the 2-day interval test-retest reliability was .87, and the six-month interval test-retest reliability was .77. In the present study, ISEL-12 had good internal consistency, with Cronbach's alpha = .89.

Quality of Life

The World Health Organization Quality of Life-Brief version (WHOQOL-BREF; World Health Organization, 1996) was used to assess participants' perceived QoL. It is a well-known QoL measure developed by the WHO (1996), which has been used throughout the world. The original WHOQOL had 100 items and was created 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 they feel their QoL was during the past 2 weeks on a 5-point Likert scale (1 = "very dissatisfied/very poor/not at all/never" to 5 = "very satisfied/good/completely/always"). The WHOQOL-BREF is scored in 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 domain. For example, the question "Do you have sufficient energy for everyday life?" is associated with participants' physically related QoL. A higher score indicates a higher QoL. In this study, the main focus was on physically related QoL, psychologically related QoL, and overall QoL.

Procedures

After Institutional Review Board approval was obtained, invitation emails including information about the study were sent to identified agencies, such as nonprofit private agencies and community support groups. The recruitment messages were also shared via parent support groups on the social media platform Facebook. After agreeing to participate, the organizations disseminated the information to their members/clients via either a listserv or website posting. Interested participants then used the direct link included in the flyer to participate by completing the anonymous survey via an online survey platform (Qualtrics.com) or mailing it back to the researchers. Each participant who completed the survey received a U.S. \$10 gift card.

Data Analysis

The survey dataset was downloaded directly from the electronic survey platform and imported into Statistical Package for the Social Science 23 for Windows (SPSS; IBM, 2015), and unnecessary data were filtered out. All analyses were conducted in SPSS.

The dependent variables investigated in this study were the overall perceived QoL and the physically and psychologically related QoL among family caregivers of adults with I/DD. The 18 independent variables (IVs) were categorized into four sets: caregiver characteristics (nine variables: age, gender, race/ethnicity, education level, annual household income, marital status, employment status, caregiver role, and residence status); characteristics of the adults with I/DD (five variables: age, types of disabilities, functional limitation, behavioural issues, and employment/education status); caregiver health status (two variables: depression, perceived stress); and caregiver resources (two variables: coping strategies and social support). These variables were chosen because of their roles in predicting QoL as judged from inspection of the raw data.

Correlational Analysis

A cross-sectional descriptive correlational design was used to examine the relationships between variables. Spearman correlation tests were conducted to explore the relationships between ordinal variables (i.e., caregiver education level and annual household income) and outcome variables (i.e., physical related QoL, psychological related QoL, and overall QoL). Pearson correlation tests were used to evaluate the associations between continuous variables (i.e., ages of caregivers and ages of adults with I/DD, functional limitations and behavioural issues of adults with I/DD, depressive symptoms, perceived stress levels, coping strategies, and social support among caregivers) and QoL. In addition, multivariate analysis of variance was conducted to assess the relationships between categorical variables (i.e., race/ethnicity, marital status, employment status, caregiver role, residence status, type of disability of adults with I/DD, and health factors of caregivers) and QoL. All statistical tests were interpreted at the significance level of .05. For multiple analyses, Bonferroni correction was used to control for type I error.

Hierarchical Regression Analysis

Second, hierarchical regression analysis (HRA) was used to validate the conceptual framework as a comprehensive model for understanding how different contextual factors affect the QoL of family caregivers of adults with I/DD. Three sets of independent variables (Table 4) were entered into the HRA model to predict the outcome variables (i.e., physical related QoL, psychological related QoL, and overall QoL). The order of entry of sets of IVs was determined on the basis of the results of the correlational analyses. Only IVs showing significant associations with QoL were entered into the HRA model. These IVs were: caregiver's age, depressive symptoms, perceived stress level, health condition, coping skills, and social support; and individuals with I/DD's age, behavioural issues, functional independence level, and residency status. Table 4 in the Results section shows the order of entry of IVs into the HRA model.

Mediation Analysis

Finally, the mediation effects of caregivers' depressive symptoms and perceived stress levels on their QoL were examined. The mediation analysis was used to determine whether caregivers' mental health conditions (depressive symptoms and perceived stress levels) mediated the relationship between adults with IDD's behavioural issues and psychologically related QoL among caregivers of adults with IDD. Two single mediation analyses were conducted by using the SPSS macro set, PROCESS (Hayes & Preacher, 2014).

Results

The demographic characteristics of the caregivers and their care recipients in this study have been summarized in Tables 2.1 and 2.2. The correlation analyses (Table 3) depict the correlation matrix.

Characteristics of the participants are summarized in Tables 2.1 and 2.2. This information was taken from the demographic section of the survey and was provided by the caregivers who completed the survey.

Table 2.1

Characteristics of Family Caregivers Who Participated in This Study

Variable	N	%
Gender		
<i>Female</i>	77	87.5
<i>Male</i>	11	12.5
Age		
30-49	24	27.3
50-59	41	46.6
60 and older	23	26.1
Race/Ethnicity		
<i>White</i>	77	87.5
<i>Non-white</i>	11	12.5
Marital Status		
<i>Married</i>	67	76.1
<i>Not married (single, divorced, or widowed)</i>	20	23.9
Employment Status		
<i>Full time</i>	43	48.9
<i>Part-time</i>	24	27.3
<i>Others (not employed or retired)</i>	21	23.4
Years of Being Caregiver		
0-10 years	11	12.5
11-20 years	27	31.7
21-30 years	34	37.8
Over 30 years	16	19.5

Residence Status		
<i>Co-reside with adults with I/DD</i>	80	90.9
<i>Does not co-reside with adults with I/DD</i>	8	9.1
Comorbid Health Conditions		
<i>Yes</i>	39	44.3
<i>No</i>	45	51.1
<i>Prefer not to answer</i>	4	4.5

Note. There were 88 participants in the study, but some data were missing; percentages in column 3 were calculated using $N = 88$.

Table 2.2

Characteristics of Adults with I/DD Whose Caregivers Participated in This Study

Variable	N	%
Age		
<i>20 and younger</i>	25	28.4
<i>21-30</i>	41	46.6
<i>31 and older</i>	22	25.0
Primary Diagnosis		
<i>ASD</i>	31	36.4
<i>ID</i>	13	14.8
<i>Other I/DD</i>	43	48.9
Employment Status		
<i>Have jobs (full time, part-time, volunteer)</i>	28	31.8
<i>Still in school</i>	28	31.8
<i>Unemployed and not in school</i>	31	35.2
Relationships		
<i>Children</i>	77	87.5
<i>Other family members</i>	9	10.2

Note: There were 88 participants in the study, but some data were missing; percentages in column 3 were calculated using $N = 88$.

Correlational Analyses

Two different correlational tests were used to examine the relationship between key IVs and outcome variables, according to specific types of variables. In addition, analysis of variance was conducted to assess group differences for various demographic variables. According to previous study results, some group differences were caregiver role (parents or others) and residency status (co-residing with the individual with I/DD or not).

Table 3*Descriptive Statistics and Correlations for Variables of Psychosocial Scales*

Variable	Pearson Correlation										
	1	2	3	4	5	6	7	8	9	10	11
1. Functional Limitation	1	--	--	--	--	--	--	--	--	--	--
2. Behavioural Issues	.094	1	--	--	--	--	--	--	--	--	--
3. Depressive Symptoms	.110	.495**	1	--	--	--	--	--	--	--	--
4. Perceived Stress	.038	.331**	.534**	1	--	--	--	--	--	--	--
5. Coping	-.276**	.042	-.178	-.022	1	--	--	--	--	--	--
6. Social Support	-.068	.161	.236*	.112	.131	1	--	--	--	--	--
7. Physical-related QoL	-.032	-.290**	-.513**	-.309**	-.097	.061	1	--	--	--	--
8. Psychological-related QoL	-.046	-.340**	-.670**	-.354**	.210*	-.013	.499**	1	--	--	--
9. Social Relationship-related QoL	.039	-.233*	-.404**	-.328*	.128	-.047	.371**	.661**	1	--	--
10. Environmental-related QoL	.058	-.226*	-.397**	-.235*	.116	.036	.506**	.599**	.451**	1	--
11. Overall QoL	.042	-.225*	-.508**	-.341**	.042	-.264*	.498**	.550**	.658**	.540**	1

Variable	Spearman Correlation	
	12.	13.
12. Highest Education	1	--
13. Annual Household Income	.280**	1

Note. * $p \leq .05$; ** $p \leq .01$. Pearson correlation was carried out to test associations between continuous and outcome variables; the Spearman correlation was used to test associations between ordinal variables and the outcome variables.

The correlation results denoted by a single or double asterisk (* $p \leq .05$; ** $p \leq .01$) in Table 3 showed that behavioural issues were positively correlated with caregivers' depressive symptoms ($r = .495^{**}$) and perceived stress ($r = .331^{**}$), and negatively correlated with physically related QoL ($r = -.290^{**}$), psychologically related QoL ($r = -.340^{**}$), social relationship-related QoL ($r = -.233^{*}$), environmentally related QoL ($r = -.226^{*}$), and overall QoL ($r = -.225^{*}$). The caregivers' depressive symptoms were also correlated with perceived stress ($r = .534^{**}$), social support ($r = .236^{*}$), physically related QoL ($r = -.513^{**}$), psychologically related QoL ($r = -.670^{**}$), social relationship related QoL ($r = -.404^{**}$), environmentally related QoL ($r = -.397^{**}$), and overall QoL ($r = -.508^{**}$). Moreover, the caregivers' perceived stress was significantly associated with physically related QoL ($r = -.309^{**}$), psychologically related QoL ($r = -.354^{**}$), social relationship related QoL ($r = -.328^{*}$), environmentally related QoL ($r = -.235^{*}$), and overall QoL ($r = -.341^{**}$). In conclusion, the caregivers' depressive symptoms and perceived stress levels negatively correlated with all domains of QoL, and depressive symptoms were positively correlated with perceived stress. In addition, behavioural issues of adults with I/DD were negatively correlated with all domains of caregiver QoL.

Hierarchical Regression Analyses

Variables entered into the hierarchical regression model are shown in Table 4. Table 5 shows the steps involved in the analysis.

Table 4

Variables Entered in the Hierarchical Regression Analysis Model

Hierarchical Regression Analysis Model	
Step 1	Caregiver characteristic: age Adults with I/DD characteristics: age, behavioural issues, functional independence level For Psychological related QoL only: residency status (living with the caregivers or not)
Step 2	Caregiver's depressive symptoms, perceived stress level For Physical and Psychological related QoL only: health conditions (whether or not the caregivers reported having one or more health conditions)
Step 3	Caregiver's coping skills, social support

Table 5

Hierarchical Multiple Regression Analysis for Prediction (Overall QoL)

Variable	R^2	ΔR^2	At Entry into Model			Final Model		
			B	SEB	β	B	SEB	β
Step 1	.123	.123*						
Caregiver Age			.197	.173	.141	.236	.157	.169
Adults with I/DD Age			-.009	.172	-.007	.096	.154	.067
Functional Limitation			.191	2.713	.008	.665	2.444	.026
Behavioural Issues			-1498	1.347	-.131*	1.989	1.360	.173
Residency			11.677	4.939	.260*	9.856	4.402	.219*
Step 2	.346	.222**						
Depression			-9.489	2.330	-.488**	-8.613	2.437	-.443**
Stress			-3.192	3.141	-.114	-3.243	3.139	-.116
Step 3	.366	.020						
Coping			1.059	2.220	.048	1.059	2.220	.048
Social Support			-5.807	3.740	-.148	-5.807	3.740	-.148

Note. Step 1: $F(5,82) = 2.305$, $p = .052$; Step 2: $F(7,80) = 6.033$, $p < .001$; Step 3: $F(9,78) = 4.994$, $p < .001$.
* $p \leq .05$; ** $p \leq .01$.

Overall, the HRA confirmed that the conceptual framework was able to predict different aspects of caregiver QoL, particularly physically related QoL (daily activity, mobility, and work capacity), psychologically related QoL (negative and positive feelings, and self-esteem), and overall QoL (Table 5). The significance was set at $\alpha = .05$. All variables accounted for 36.6% of the variance in the caregivers' overall QoL scores, thus indicating good support for use of the

theoretical framework. Slightly more than 12% of the caregivers' overall QoL variance was accounted for by the characteristics of caregivers and adults with I/DD in step 1 ($R^2 = .123$; $F(5, 82) = 2.305$; $p = .052$). In step 2, the caregivers' mental health-related variables accounted for 34.6% of the variance ($R^2 = .346$; $F(7, 80) = 6.03$; $p < .001$); a significant amount of the additional variance in overall QoL beyond this value was explained by the variables for the characteristics of caregivers and adults with I/DD entered in step 1. In step 3, ($R^2 = .366$; $F(9, 78) = 4.994$; $p < .001$), the change in R^2 was statistically insignificant (from .222* to .02) after the caregiver resource variables (i.e., coping strategies and social support) were entered into the equation, thus indicating that these two variables did not contribute to the variance in caregivers' overall QoL. In the final model, both residency status ($\beta = .219^*$) and caregivers' depressive symptoms ($\beta = -.443^{**}$) were found to significantly contribute to the variance in the overall QoL score when other variables were held constant.

Mediation Analysis

Two single mediation analyses were conducted to determine whether caregivers' depressive symptoms and perceived stress levels mediated the relationship between behavioural issues of adults with I/DD and psychologically related QoL among family caregivers.

In the first mediation analysis, the results showed that when the mediator (i.e., depressive symptoms) was included, the behavioural issues of adults with I/DD no longer predicted psychologically related QoL ($b = .048$; $t(86) = -.449$; $p = .655$). In the second mediation analysis, the behavioural issues of adults with I/DD and caregivers' perceived stress levels predicted the caregivers' psychologically related QoL; however, after the mediator (i.e., caregiver's perceived stress) was included, the behavioural issues of adults with I/DD no longer predicted psychologically related QoL among caregivers ($b = -.211$, $t(86) = -1.975$, $p = .052$, $> .05$). These results are suggestive that depression and stress, triggered by the behavioural issues of adults with I/DD, affect psychologically related QoL among caregivers, and that the effect of depression is much stronger than that of stress.

Discussion

This study revealed several important findings. First, several significant relationships were found from the correlational analyses, and HRA suggested that the following variables significantly predicted caregiver QoL in the current study: age of caregivers and adults with I/DD; behavioural issues of adults with I/DD; and depressive symptoms, perceived stress, coping strategies, and social support of caregivers. Specifically, physically related QoL, psychologically related QoL, and overall QoL significantly correlated with the behavioural issues of adults with I/DD and the depressive symptoms and perceived stress levels of caregivers. That is, the more behavioural issues that an adult with I/DD exhibits and/or the more depressive symptoms or perceived stress that a caregiver experiences, the lower the caregivers' expected physical, psychological, and overall QoL. A previous study has suggested that maternal depressive symptoms are highly correlated with behavioural problems in children with ASD (Feldman et al., 2007). In addition, children's social deficits have been found to be associated with depressive symptoms and parental stress (Serrata, 2012). The present study further confirmed that

behavioural issues of adults with IDD were negatively correlated with family caregivers' physical health- and psychological health-related QoL, as well as their overall QoL.

Second, the residency status (i.e., residing with the caregiver or not) of people with I/DD was associated with the caregivers' psychologically related QoL and overall QoL. These findings echoed previous studies indicating that caregivers who reside with their adult children with an I/DD have significantly higher depressive symptoms, having more negative mental health issues, and poorer health related QoL than those who do not (Krauss et al., 2005; Seltzer et al., 2004).

Third, caregivers' depressive symptoms and perceived stress were negatively correlated with caregivers' physical, psychological, and overall QoL in this study. In fact, caregivers' depressive symptoms were so significantly correlated with outcomes that they overshadowed the other variables' effects on QoL. Depressive symptoms were prevalent among mothers of children, adolescents, and young adults with I/DD in keeping with previous studies (Abbeduto et al., 2004; Feldman et al., 2007). Past studies have suggested that depressive symptoms are common among caregivers of children with I/DD, and our results indicate that this phenomenon may also apply to caregivers of adults with I/DD.

Moreover, the results of the mediation analysis indicated that caregivers' depressive symptoms and stress levels each mediate the relationship between the behavioural issues of adults with I/DD and the psychologically related QoL of caregivers. This result is similar to those of many past studies suggesting that the stress originating from providing care for people with IDD can affect not only caregivers' health condition but also their overall functioning, in aspects 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 suggested that family caregivers' mental health status should be evaluated and emphasized, particularly among caregivers of adults with significant behavioural issues, because these two factors were highly correlated with caregivers' psychologically related QoL. These findings raise the possibility that caring for adults with I/DD who have more behavioural issues does not necessarily predict lower psychological QoL, as long as good mental health status is maintained, and the mental capacity of people caring for this population can be extended.

Finally, aging caregivers may also experience stress from other causes, 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 the study participants (44.3%) reported having at least one health condition. In the current study, arthritis was the most commonly reported health condition. Other health conditions reported by caregivers included high blood pressure, back pain, and depression, and these results were similar to those of a previous study indicating osteoarthritis as a health condition reported by the aging caregivers that may affect their ability to continue providing care (Haley & Perkins, 2004).

However, most of the demographic variables did not account for the variance in the outcome variables. For example, previous studies have indicated that race/ethnicity might result in different levels of depressive symptoms among caregivers and that non-Hispanic mothers of adults with I/DD have lower self-reported depressive symptoms than Latina mothers (Blacher & McIntyre, 2006), and black caregivers have been found to be more resilient to negative situations than white caregivers (Haley et al., 1995). In the current study, one limitation is that most caregivers were white; therefore, racial/ethnic groups could not be compared.

Limitations and Future Implications

Limitations

This study has several limitations. First, given the time constraints and the nature of the study's cross-sectional design, this study provides only a snapshot of the current QoL of family caregivers of adults with I/DD. Causal relationships between variables cannot be revealed with only observational data. A longitudinal study would be beneficial to allow researchers and practitioners who work with adults with I/DD and their families to gain more insight into how aging affects caregiving experiences. Second, the exclusive use of the online platform might have excluded people who did not have internet access or did not belong to any agencies or listservs from the sample of the current study. In addition, although the study design did not specify the geographical location, most participants were from the United States, thus making the study results not generalizable to other countries. Finally, the study was not able to provide multiple languages or multi-cultural appropriate adaptation; therefore, this study might have excluded people unable to participate because of language barriers.

Future Implications

This study provides information for practitioners on the shared challenges and needs of caregivers of adults with I/DD. In future research, before any further generalization of the study results, increasing the sample size should be a priority, and the recruiting process should be carefully designed before studies are performed. Building relationships with families before the study would be extremely important and helpful, not only to increase the willingness of families to join the study but also to better understand what really matters in their lives. In addition, owing to the time constraints, investigations of many other variables were not conducted herein. In the future, researchers should consider paying more attention to those variables to further determine their roles among caregivers of adults with IDD in relation to caregiver QoL. Although other variables, such as burden, were not included in this study, they might be worth researching and discussing as well. Many studies have examined the level of burden among caregivers of people with disabilities (e.g., Chou et al., 2011; Raina et al., 2004). Thus, to develop a truly comprehensive conceptual framework to predict QoL, these variables should be carefully considered. Furthermore, on the basis of previous research, group differences exist among caregivers for people with different disabilities. For example, mothers of children with autism spectrum disorder more commonly report having depressive symptoms than mothers of children with ID (Feldman et al., 2007). In the present study, the group differences were not examined, because this study was designed to explore the population as a whole. In the future, the differences, if any, between various diagnostic groups are worthy of evaluation, to provide more tailored services to caregivers.

We also recommend that practitioners more closely examine caregivers' mental health status, particularly their depressive symptoms and stress levels. The study results indicated that the caregivers' depressive symptoms highly correlated with their QoL, as well as mediating the relationship between behavioural issues and QoL. Educating caregivers to adequately manage their depression and stress should improve not only caregivers' mental health and QoL, but also

the overall QoL of people with I/DDs. Abbeduto et al. (2004) have indicated that practitioners should provide timely training to control behavioural issues in people with IDD so that caregivers' stress levels can be lessened.

Our results indicate that residing with adults with I/DD affects caregivers' psychologically related QoL. Therefore, practitioners should promptly assess family caregivers' needs to provide necessary interventions, support, and resources. As a previous study has suggested, if caregivers' needs were met and the social welfare system were improved, family caregivers' ability to provide care to adults with I/DD could be extended so that caregivers would not need to jeopardize their own physical and mental health (Seltzer et al., 2011).

Key Messages from This Study

People with disabilities. Your family's well-being is as important as your well-being. Family is what moves us along.

Professionals. When working with people with disabilities, we should keep their family's mental health status in mind to truly provide complete services to achieve maximized outcomes.

Policymakers. It is important to also look at their caregivers' quality of life when serving individuals with I/DD. A wraparound service should also be given to the caregivers to maximize their capacity to provide care, and in turn, individuals with I/DD's quality of life would also be improved.

Messages clés de cette étude

Personnes ayant une incapacité. Le bien-être de votre famille est aussi important que le vôtre. La famille est ce qui nous fait avancer.

Professionnels. Lorsque nous travaillons avec des personnes ayant une incapacité, il faut garder en tête l'état de santé mentale de leur famille pour réellement dispenser des services complets et, ainsi, maximiser les résultats.

Décideurs. Lorsque l'on souhaite soutenir les personnes ayant une DI ou un TD, il est important d'examiner également la qualité de vie de leurs aidants naturels. Un service global devrait aussi être offert aux aidants pour maximiser leur capacité à donner des soins et, par ricochet, améliorer la qualité de vie des personnes ayant une DI ou un TD.

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