Predictors of Life Satisfaction among Caregivers of Children with Developmental Disabilities in South Korea

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Abstract

It is known that factors such as socio-demographic characteristics and care-related stressors among caregivers of children with developmental disabilities (CDD) predict their life satisfaction (LS). Due to a lack of data, however, very little is known about the predictors of LS in South Korea. This study aims to examine factors associated with LS among the caregivers of CDD using the recently collected data from the national survey on people with developmental disabilities in South Korea. Structural Equation Modeling (SEM) was performed including a total of 390 caregivers participated in the survey. Key findings are as follows. (1) Both child’s age and caregiver’s age were negatively associated with caregivers’ LS, whereas the severity of child’s disability and monthly family income were positively associated with the caregivers’ LS. (2) While caregiving stress and perceived financial burden were negatively associated with LS, amount of time for caring was not significantly associated with LS. Based on the findings, discussion and implications for theory and practice are provided.

Keywords: life satisfaction, socio-demographic characteristics, time demands of caring, caregiving stress, perceived financial burden, caregivers, children with developmental disabilities

1. Introduction

1.1 Current trends in South Korea

In South Korea, the registered individuals with disabilities were more than 2.5 million as of the end of December 2012, occupying 4.9% of the whole population of South Korea. Among the population with disabilities, individuals with intellectual disability (ID) were 6.9% (n=173 257), and those with autism were 0.7% (n=16 906) (Ministry of Health and Welfare [MOHW], 2012). Intellectual disability and autism are collectively defined as developmental disabilities (DD) in South Korea. Children and adolescents from the age of 0 to 19 years make up the largest group of individuals diagnosed with DD (30.1%) (MOHW, 2012). According to Cho et al. (2011)’s study on people with DD and their families, the first national survey on people with DD, primary caregivers of CDD were mainly parents (97.9%). The similar finding was reported in 2011 National Survey on Persons with Disabilities (MOHW & KIHASA, 2011). The CDD aged less than 18 were reported to be mainly cared for by their parents, and the majority (91.1%) was found to be living with their parents. In general, it is known that the CDD are vulnerable in functioning; they require continuous care from their primary caregivers. Regarding their independence in daily activities, 89.9% of CDD required some or most help from others, mostly from their parents. Based on their functional capability measured by ADLs (activities in daily living) and IADLs (instrumental activities in daily living), they needed others’ assistance in various activities. For children with ID, the caregivers provided most assistance in bathing and changing clothes, and for the children with autism, parents provided help in bathing, tooth-brushing, dressing, and taking a meal (MOHW & KIHASA, 2011). As for IADLs, the results showed that over 90% of children with ID needed assistance in shopping, preparing food, doing house chores and laundry, and managing money; all children with autism needed assistance in all activities such as purchasing, preparing a meal, doing house chores and laundry, taking medicine, and managing money. Under these circumstances, the caregivers are mainly parents who are taking care of their children in every activity in daily life. Apart from helping the CDD in daily activities, the caregivers also experience untold financial, psychosocial, and emotional difficulties from the birth of CDD. They are responsible for children’s disability-related expenses from rehabilitation to education and other special needs (Bae, 2005), and feel...
depressed because of never-ending care for their children and isolated because of lack of leisure and interpersonal relationship. Although developmental disabilities are diagnosed in early childhood, it is unlikely that the disabilities can be recovered and thus these disabilities do impose heavy burden on the caregivers and family (Lee & Park, 2013). The caregivers of CDD are, in particular, at risk for greater distress and are more vulnerable to negative outcomes such as depression, social isolation, and spousal relationship difficulties comparatively than the parents of children with other disabilities (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2011; Hodapp, Ricci, Ly, & Fidler, 2003). Thus, it is very critical to investigate overall evaluation on life among the parents and family of CDD as LS reflects every positive and negative situation of life experienced by them. In addition, as parents are the most influential factor affecting children’s healthy growth, identifying their care-associated situations and various predictors which influence their level of LS will be an important issue.

1.2 Literature Reviews

Generally, LS is defined as an individual’s judgment of how satisfied they are with their present state of affairs based on a comparison with criteria which each individual sets for him or herself (Diener, Emmons, Larsen, & Griffin, 1985). In other words, LS can be defined as an individual’s cognitive appraisal on his or her overall life. As the concept of LS reflects cognitive aspects of individuals, it is important to understand how caregivers of the CDD perceive their life and assess their LS as it reflects their cognitive appraisal of stressors and/or burden that may be part of caring for their CDD. However, studies examine LS of caregivers of the CDD remain quite scarce. This is particularly so as scholars have often interchangeably used the concept of LS with quality of life (QoL) and subjective well-being (SWB). For example, Malhotra, Khan, and Bhatia (2012) examined QoL of parents of children with mental retardation and autism, and found that all the four domains of QoL were lower (i.e., physical health, psychological well-being, social relationships, and environment) compared with parents of healthy children. Cummins (2001), on the other hand, employed the concept of SWB in reviewing qualitative and quantitative researches on people caring for a family member with a severe disability, and found that caregivers experienced abnormally low SWB. Olsson, Larsman, and Hwang (2008) examined well-being of the caregivers; particularly how satisfied the caregivers of children with ID are with their life and how healthy they are, and found that the parents of children with ID exhibited a lower level of well-being compared to the parents of children without disabilities. Darling, Senatore, and Strachan (2011) examined LS of fathers of children with various disabilities such as DD, attention deficit disorder, emotional-behavioral disability, and speech-language disability, and revealed that lower level of LS was found among the fathers of children with disabilities compared to non-caregiver and the caregivers of typically developing children. Similar findings were also reported in Burton-Smith and his colleagues’ study (2009) on caregivers of individuals with and without disabilities, and yielded consistent results. Burton-Smith et al. (2009) showed the level of LS among the caregivers of family member with various disabilities (75% were ID) was significantly lower than that of the general population. In Borg and Hallberg’s study (2006), frequent caregivers had decreased LS than less frequent caregivers and non-caregivers. Despite using different measures, the findings all point to the same conclusion that the caregivers have lower LS, and these consistent findings regarding LS in caregivers give us space to further investigate the influential predictors.

The studies on LS of caregivers regarded caregiver’s gender, age, and household monthly income as important socio-demographic variables (Kabasakal, Girli, Totan, & Aysan, 2012; Kaufman, Kosberg, Leeper, & Tang, 2010; Predescu & Şipoş, 2013; Yong, Hwang, Ko, & Kim, 2009). However, in most studies, these socio-demographic characteristics were considered as control variables; thus no detailed explanations were mentioned. Malhotra et al. (2012) found that mothers of CDD actually reported lower QoL than fathers, but the difference was not statistically remarkable. Many researches, however, predicted that as mothers were main caregivers of CDD, they suffered stronger impairment than fathers in terms of QoL (Allik, Larsson, & Smedje, 2006; Yamada et al., 2012), and fathers typically reported lower levels of psychological distress than their spouses (Emerson et al., 2010). The caregivers’ age were shown to be insignificantly related to their LS (Kabasakal et al., 2012), while household income was positively associated with their LS (e.g., Kaufman et al., 2010; Yong et al., 2009). In spite of inconsistent findings and insignificant association with LS, these caregiver-related factors are of importance because they may further explain how caregivers’ particular characteristics affect LS. As for characteristics of CDD, children’s age, disability types, and severity of disability were selected as predictors of LS of caregivers in the present study. In Yong et al. (2009), psychological well-being among mothers of children with disabilities (e.g., autism and mental retardation) was higher as children grew up, while the opposite finding was also reported that mothers rearing children with disabilities at higher age had lower QoL (Kim, Lee, & Kim, 2011). As the previous researches have been conducted in a cross-sectional analysis, repetition of the results is required. As for disability types, despite that intellectual
disability and autism are collectively regarded as developmental disabilities or developmental disorders (Malhotra et al., 2012), they have different relationship with LS. Some studies show that mother of children with pervasive developmental disorders have a lower QoL than the mothers of children with mental retardation and other chronic disease because of serious symptoms and behavior problems revealed by children with autism (Mugno, Ruta, D’ Arrigo, & Mazzone, 2007; Yamada et al., 2012). In Malhotra et al. (2012), on the other hand, little differences in QoL were observed between caregivers of children with mental retardation and autism. Researchers explained that caregivers who have higher time demands of caring for children with disabilities may have less spare time for rest and leisure, which may adversely affect their satisfaction on life.

The caregivers’ perceived burden on childcare can be represented by the level of caregiving stress. Childcare can also cause stress in families with normally developing children; such stress generally decrease overtime as children grow up (Allen, Bowles, & Weber, 2013). However, for the caregivers of CDD, care may need to be maintained throughout the child’s life (Allen et al., 2013). Parenting can be a lifelong occupation, which may exhaust all their physical, psychological, and social competence. Singer & Farker (1989) also explained that parents with children with disabilities often experience financial burden, mental and physical fatigue, loss of job opportunity, limitation in outdoor and leisure activities, social isolation, and marital conflict. In addition, parents’ guilt toward their children, sadness, hopelessness, and frustration may amplify tension and conflict in family life (Chung & Cho, 2013), resulting in lower LS. Despite the importance of understanding how such care-related stress is associated with LS among the caregivers of CDD, only a handful studies have investigated the relationship between caregiving stress and LS among them.

It is well-known that in general, children with disabilities and their families are significantly more likely to live in poverty than typically developing peer and their families (Bachman & Comeau, 2010; Bauman, Silver, & Stein, 2006; Parish & Cloud, 2006). This is because the families of CDD experience increased financial burden due to the high cost of care (Newacheck & Kim, 2005; Parish & Cloud, 2006) such as medical care, rehabilitation service, specialized education, and transportation. As of 2006, the proportion of family with disability living under the national minimum in South Korea was 21%, which was about three times higher than the family without disability (7.3%) (Yoon & Kim, 2009). A recent study on 2011 National Survey on Persons with Disabilities (MOHW & KIHASA, 2011) also revealed that the family of children with ID spent 300 thousand Korean currency per month (approximately 295 US dollars), and the family of children with autism spent 547 thousand Korean currency per month (approximately 538 US dollars) for their children. Similar findings have also been reported in other countries as the disability-related cost spent by families with disabilities were three times higher than family without disabilities (Russell, 2003). The elevated cost of raising children with disabilities means these families must have stable and adequate income to provide the specialized care to meet their children’s needs (Parish & Cloud, 2006). However, in reality, the child’s need of additional care may reduce the parents’ opportunities to work full time (Svedberg, Englund, Malker, & Stener-Victorin, 2010). Yet, as the families receive very limited financial support to care for their CDD (Parish, Pomeranz-Essley, Braddock, & Taylor), they again look for part-time work, at least to some extent, to compensate for their reduced income (Svedberg et al., 2010). Thus, higher out-of-pocket cost, routine expenses, less job stability, and the loss of employment income are likely to exacerbate the financial condition of families of children with disabilities. When the financial well-being of the family is invaded, family members’ lives will likely to be affected.
In sum, the caregivers’ perception of their life in caring for CDD is very critical. However, only a small number of researches regarding LS among the primary caregivers of CDD were found in South Korea. Even among these studies, care-related stress among the caregivers of CDD has been overlooked. Thus, the present study aims to investigate the level of LS and the influential predictors of LS among the caregivers of CDD based on the domestic and international literature reviews and with recently collected data. More specifically, the associations among the socio-characteristics and care-related stressors of the caregivers of CDD and their LS are examined.

The research model was formulated as in Figure 1.

![Research model](image)

The research questions were developed as follows:

RQ1: Do socio-demographic variables (children’s age, disability types, and severity of disability, caregiver’s gender and age, and monthly family income) affect LS of the caregivers?

RQ2: Do care-related variables affect (time demands of caring, caregiving stress, and perceived financial burden) LS of the caregivers?

2. Method

2.1 Sample and Data

The present study used a representative data from ‘2011 Policy Recommendations for Supporting People with Developmental Disabilities and their Families Based on a Needs Assessment Survey’ (Cho et al., 2011), the first survey conducted on a national sample of individuals with DD (i.e., intellectual disability and autism). The survey was collected from 17 October 2011 to 28 November 2011, using the face-to-face interview by skilled interviewers. The number of individuals with DD was sampled from the National Disability Registration Database of the Ministry of Health and Welfare as of August 2011. At the time of survey, the total population with DD was counted 180,869; individuals with intellectual disability were 165,371 (91.4%), and individuals with autism were 15,498 (8.6%) (MOHW & KIHASA, 2011). A total of 1,500 caregivers of individuals with DD were finally included in the data; and 390 caregivers of CDD less than 18 years of age were selected as the study sample of this study.

2.2 Measurements of Variables

2.2.1 Life Satisfaction

Life satisfaction measures individuals’ perceived quality of life in various life domains based on individual preferences (Henrich & Herschbach, 2000). The LS scale is included as a latent variable in the analytic model with seven sub-domains: health, annual household income, residential environment, family relationship, career, social relationship, and leisure. It is scored on a five-Likert scale with value of one indicating ‘very unsatisfied’ and five indicating ‘very satisfied’. The higher total scores indicate a higher level of satisfaction.
2.2.2 Socio-demographic Variables
Six manifest variables are included: children’s age (less than 18 years), children’s disability types (intellectual disability or autism) and the severity of disability (level one referring to the severest), caregiver’s gender (male and female) and age, and monthly family income.

2.2.3 Time Demands of Caring
Time demands of caring assess average hours caregivers spend on caring for their CDD per day during the past month. Caring activities include keeping children safe and preventing them from causing harm to others. This variable is included as a manifest variable in the model; and more hours of caring indicate higher time demands of caring.

2.2.4 Caregiving Stress
Caregiving stress is measured by the shortened and revised version of the original Questionnaire on Resources and Stress (QRS-F) developed by Holroyd (1974). The QRS-F was modified to 52 questions by Friedrich, Greenberg, and Crnic (1983) in a ‘true (1)’ or ‘false (0)’ format. The QRS-F, a frequently and widely used tool to measure stress of parent of children with disabilities (Glidden & Floyd, 1997; Honey, Hastings, & Mcconachie, 2005), is composed of four domains: parent and family problems (stressful aspects of the impact of a child with a disability on parents and the wider family, 20 items), pessimism (parents’ pessimistic beliefs about the child’s future, 11 items), child characteristics (features of the child that are associated with increased demands on parents, 15 items), and physical incapacity (the extent to which the child is able to perform a range of typical activities, 6 items) (Honey et al., 2005). The mean of each domain is included as an indicator of the latent caregiving stress variable.

2.2.5 Perceived Financial Burden
Perceived financial burden measures to what extent the caregivers experience stress with the following three additional expenses: health care, education, and transportation for CDD. These three areas made up the latent variable, perceived financial burden, and are measured on a four-point Likert scale, with one for ‘not demanding at all’ and four for ‘very much demanding’.

2.3 Analytic Techniques
The socio-demographic characteristics of the CDD and their caregivers and descriptive findings of major variables were analyzed through IBM SPSS Statistics 19.0. The effect analysis regarding the association between the variables of interest and LS of the caregivers was analyzed through structural equation modeling (SEM) using Amos 19.0. SEM is conducted in two steps: a measurement model analysis and a structural model analysis. It provides path coefficients and the overall goodness of fit of the proposed model which is evaluated by several model fit indices such as a $\chi^2$ goodness of fit, RMSEA, IFI, and CFI. In the current study, IFI and CFI values of .9 or greater (Bentler, 1990; Bollen, 1989) and the values of RMSEA in range of .05 to .08 have been taken to indicate an acceptable fit (Browne & Cudeck, 1993; Steiger, 1990).

3. Results

3.1 The Characteristics of the Study Sample

<table>
<thead>
<tr>
<th>Variables</th>
<th>Frequency (%) or $M(SD)$</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child’s age</td>
<td>11.84 (3.538)</td>
<td>3-17</td>
</tr>
<tr>
<td>Child’s disability type</td>
<td></td>
<td>0-1</td>
</tr>
<tr>
<td>Intellectual disability$^*$</td>
<td>209 (53.6)</td>
<td></td>
</tr>
<tr>
<td>Autism</td>
<td>181 (46.4)</td>
<td></td>
</tr>
<tr>
<td>Child’s severity of disability</td>
<td></td>
<td>1-3</td>
</tr>
<tr>
<td>Level 1 (the severest)</td>
<td>146 (37.4)</td>
<td></td>
</tr>
<tr>
<td>Level 2</td>
<td>131 (33.6)</td>
<td></td>
</tr>
<tr>
<td>Level 3$^*$</td>
<td>113 (29.0)</td>
<td></td>
</tr>
<tr>
<td>Caregiver’s gender</td>
<td></td>
<td>0-1</td>
</tr>
<tr>
<td>Mothers</td>
<td>324 (83.1)</td>
<td></td>
</tr>
<tr>
<td>Fathers$^*$</td>
<td>66 (16.9)</td>
<td></td>
</tr>
<tr>
<td>Variables</td>
<td>Frequency (%) or M(SD)</td>
<td>Range</td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Caregiver’s age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20s and less*</td>
<td>6 (1.5)</td>
<td>1-5</td>
</tr>
<tr>
<td>30s</td>
<td>121 (31.0)</td>
<td></td>
</tr>
<tr>
<td>40s</td>
<td>227 (58.2)</td>
<td></td>
</tr>
<tr>
<td>50s</td>
<td>33 (8.5)</td>
<td></td>
</tr>
<tr>
<td>60s and over</td>
<td>3 (0.8)</td>
<td></td>
</tr>
<tr>
<td>Monthly family income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(unit: 10,000KRW) (N=387)</td>
<td>236.22 (146.781)</td>
<td>0-1200</td>
</tr>
<tr>
<td>Time demands of Caring</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(unit: hours)</td>
<td>6.53 (5.879)</td>
<td>0-24</td>
</tr>
<tr>
<td>Caregiving stress</td>
<td>0.57 (.190)</td>
<td>0-1</td>
</tr>
<tr>
<td>Perceived financial burden (N=247~259)</td>
<td>2.85 (.795)</td>
<td>1-4</td>
</tr>
<tr>
<td>Life satisfaction (N=177~390)</td>
<td>3.05 (.687)</td>
<td>1-5</td>
</tr>
</tbody>
</table>

Note: Variables with asterisk (*) are coded as 1 in data.

The descriptive statistics of the socio-demographic and care-related characteristics of the study sample are displayed in Table 1. Five child-related variables and five caregivers-related variables were analyzed. The correlations among the variables were between .008 and .618. The multicollinearity was not detected as the VIF ranged between 1.057 and 1.342. The normality was satisfied with the skewness between 0.22 and 1.771 and kurtosis between .122 and 2.072.

### 3.2 Analysis of Research Model

![Figure 2. Final SEM model](image)

A specified model with three latent and seven manifest variables was specified. The latent variables were LS, caregiving stress, and perceived financial burden. Before conducting structural analysis, the measurement model analysis was performed. The test statistics for the measurement model were $\chi^2 (74)=183.602$ (p<.001), RMSEA =.062, IFI=.94, and CFI=.939. These results indicated that the measurement model was appropriate to move on to the next step to the structural model analysis. The test statistics for the structural model were $\chi^2$
(151)=363.889 (p<.001), RMSEA =.06, IFI=.911, and CFI=.907. These results showed that the structural model had an acceptable fit. Figure 2 shows the final SEM model with its significant paths and covariances.

Table 2. Coefficients of the independent variables and the covariates

<table>
<thead>
<tr>
<th>Variables</th>
<th>Standardized Estimate (β)</th>
<th>Unstandardized Estimate (B)</th>
<th>S.E.</th>
<th>C.R.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Socio-demographic characteristics</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child’s age</td>
<td>-.144**</td>
<td>-.022</td>
<td>.008</td>
<td>-2.785</td>
</tr>
<tr>
<td>Child’s disability types</td>
<td>-.063</td>
<td>-.063</td>
<td>.051</td>
<td>-1.357</td>
</tr>
<tr>
<td>Child’s disability severity</td>
<td>.132*</td>
<td>.089</td>
<td>.037</td>
<td>2.394</td>
</tr>
<tr>
<td>Caregiver’s gender</td>
<td>-.014</td>
<td>-.021</td>
<td>.065</td>
<td>-.319</td>
</tr>
<tr>
<td>Caregiver’s age</td>
<td>-.108*</td>
<td>-.090</td>
<td>.043</td>
<td>-2.112</td>
</tr>
<tr>
<td>Monthly family income</td>
<td>.323***</td>
<td>.040</td>
<td>.007</td>
<td>5.971</td>
</tr>
<tr>
<td><strong>Care-related variables</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time demands of caring</td>
<td>-.071</td>
<td>-.007</td>
<td>.005</td>
<td>-1.433</td>
</tr>
<tr>
<td>Caregiving stress</td>
<td>-.455***</td>
<td>-1.369</td>
<td>.226</td>
<td>-6.058</td>
</tr>
<tr>
<td>Perceived financial burden</td>
<td>-.145*</td>
<td>-.145</td>
<td>.058</td>
<td>-2.527</td>
</tr>
</tbody>
</table>

Note: ***p<.001, **p<.01, *p<.05; S.E. (Standard error); C.R. (Critical Ratio)

The path coefficients are presented in Table 2. Among the socio-demographics, children’s and the caregivers’ age were reversely associated with LS of the caregivers (β=−.144, p<.01; β=−.108, p<.05), whereas the severity of children’s disability and monthly family income were positively associated with caregivers’s LS (β=.132, p<.05; β=.323, p<.001). In other words, the older the CDD and their caregivers were, the less satisfied caregivers were with their life in general. On the other hand, the caregivers with children who have severe disability and with higher monthly family income were more likely to be satisfied with their life. Disability types and caregivers’ gender, however, were shown to be insignificantly related to LS. The time demands of caring for CDD was negatively but insignificantly affected LS of the caregivers (β=−.071, p=.152). The absolute amount of caregiving time was not statistically related to their satisfaction with life. However, caregiving stress of the caregivers negatively affected their LS (β=−.455, p<.001). The caregivers who experienced higher caregiving stress reported lower level of LS. In addition, perceived financial burden of the caregivers had a significant negative relation to their LS (β=−.145, p<.05). That is, the caregivers who perceived their financial burden as more demanding experienced lower satisfaction with their life.

4. Discussions

Based on the data from 390 caregivers of CDD, this study examined the predictors of overall LS of the caregivers. The findings revealed that the age of the CDD and the caregivers affected the caregivers’ LS that the older CDD and the older caregivers reported to be less satisfied with their life. Unlike typically developing children whose care demands usually lessen as children grow up (Francis-Connolly, 1998), care needs of children with severe disabilities do not decrease with advancing age (Curran, Sharples, White, & Knapp, 2001). In addition, the cumulative care demands along with ageing parents’ deteriorating health will impose greater burden on the caregivers. A research on the middle-aged and elderly caregivers reported that the caregivers, regardless of intensity of caregiving, had lower LS as they aged. It is understandable that an escalated need of CDD and a decrease in physical health of the caregivers coupled with being burnout due to a long period of care ultimately lead to lowering of LS among the caregivers.

As for the disability-related factors, the CDD’s severity of disability was positively related to the caregivers’ LS, whereas disability types were insignificantly associated with LS. As Cummins (2005) explained, the kinds and the degree of difficulties families experience often vary depending on the degree and the types of disability of their children. Generally in the literature, the increase in severity of disability of children negatively affected LS in the caregivers (Smith, Birchwood, Cochranle, & George, 1993; Wang et al., 2004). However, the finding of the present study yielded the opposite finding. This finding is also reported in Chou and colleagues’ research (2007) on the caregivers of adult children with ID in Taiwan that the caregivers of children with severe disability reported higher satisfaction toward their life. In Taiwan, families of people with severe or profound disability are eligible to receive a higher level of governmental subsidy than people diagnosed with mild disabilities. Thus, it was suggested that the family caregivers of people with severe or profound disabilities might receive much more formal support than those of people with mild disabilities, resulting in a differential impact on the QoL of the
family caregivers. As Taiwan’s service delivery system is very similar with that of South Korea, the same argument can be made. In South Korea, active policy measures have been developed and implemented for the welfare of families of CDD, expanding services and programs to support them. However, as these services and programs are particularly targeting the families of children with severe disabilities rather than those of children with mild or moderate disabilities, they consequently receive more governmental support than the caregivers of CDD with mild or moderate disabilities, which may be very effective in improving the overall LS for the caregivers of children with severe DD. Additionally, the types of the disability did not affect LS, which was consistent with other studies (Choi & Lee, 2005; Malhotra et al., 2012). Yet, other studies revealed that the mothers of children with pervasive developmental disabilities tend to have lower QoL than the mothers of children with mental retardation (Mugno et al., 2007). Moreover, the mothers with autistic children were shown to be more stressed and had higher levels of somatic complaints as well as anxiety and depression compared with the mothers of intellectually disabled children (Holroyd & McArthur, 1976; Weiss, 2002). The inconsistency in the findings regarding the effect of disability types between ID and autism requires further investigation.

Lastly, monthly family income was positively associated with the LS of the caregivers. Similar findings have been reported in previous studies (e.g., Chou, Lin, Chang, & Schalock., 2007; Ravindranadan & Raju, 2008; Wang et al., 2004), indicating that family income is an important source of higher out-of-pocket expenditures spent for CDD, and that having stable and sufficient family income prevents the family with CDD from falling into financial hardship. Korean government provides several types of financial assistance to the families of CDD such as the Child with Disabilities Allowance and financial support for education, medical care, and rehabilitation expenses. However, the support system is very selective. In order to get benefit from these financial supports, CDD’s disability and general situation should meet the eligibility criteria of age, income level, and severity of disability. As the finding shows that the financial situations these families experience significantly affect their life in general, it calls for expansion of financial services in South Korea.

Regarding the care-related stressors of the caregivers, first, the time demands of caring was negatively associated with LS among the caregivers though the association was statistically insignificant. In Crowe and Florez’s research (2006), the mothers of children with disabilities rated the quality of their days significantly poorer than mothers of children without disabilities as the greatest amount of waking time spent by the mothers of children with disabilities was on childcare and the least amount of time spent was in recreation. Additionally in Borg and Hallberg’s research (2006), LS among the caregivers between the ages of 50 and 89 years was examined, and the finding showed that the frequent caregivers had substantially lower levels of LS compared to the less frequent caregivers and the non-caregivers. In other words, the additional time demands of caring adversely affect the psychological adjustment and the QoL of caregivers (Sawyer et al., 2010). However, what is noteworthy is that the relationship between the amount of caregiving time and their LS. The association was not significant and this may be explained by Lazarus and Folkman (1984)’s argument on cognitive appraisal that whether a particular individual-environment relationship is stressful or not is judged based on cognitive appraisal by the individual. More specifically, the actual amount of time spent on caring may not weigh as much as how individuals perceive their time use (Robinson & Godbey, 2000). Two studies (Sawyer et al., 2010; 2011) on the association between maternal mental health and time demands of caring for children with autism and with cerebral palsy also demonstrated that the amount of time spent for caregiving was not statistically significantly related to maternal mental health; however, time pressure significantly affected their mental health. Such findings indicate that for caregiving, it is the perception of time pressure, rather than the actual spending of time that influences caregivers’ perception of their LS (Robinson & Godbey, 2000).

Second, a higher level of caregiving stress perceived by the caregivers of CDD resulted in a lower level of LS. Previous literature on caregiving stress and well-being among the caregivers supported these findings (Darling et al., 2011; Hastings et al., 2005). For example, a study conducted by Bergström, Eriksson, von Koch, and Tham (2011) showed that informal caregiver would often experience caregiver burden (Rigby, Gubitz, & Phillips, 2009), and the caregiver burden was associated with a lower level of LS. In general, CDD tend to be dependent on their caregivers across various aspects of their life, and the caregivers usually provide assistance in looking after children’s basic needs such as using transportation, bathing, and others. The excessive amount of time spent for caregiving, children’s behavioral problems, severity in disability, a lack of time for house chores, leisure, and spending time with their other children, sleep deprivation, feelings of frustration and anxiety for future can be accumulated and such layers of stress are likely to affect the caregivers’ perception on life. In Korean society, a duty of caring for children with disabilities are substantially imposed upon their parents and caring for children with disabilities is regarded as a personal problem. In addition to such social perception, the limited government support for the families often function as barriers in maintaining LS.
Third, perceived financial burden experienced by the caregivers was also associated with their LS that among the caregiver who regarded out-of-pocket costs for health care, educational, and transportation expenditures required for their CDD as demanding reported lower LS. This result was consistent with Lee, Kim, and Lee (2007) in that financial burden caused by caring for children with disabilities incurred financial, psychological, social, and physical stress, and this, in turn, lowered QoL among the mothers. As it is known, having children with disabilities often lead to added expenses (Parish, Seltzer, Greenberg, & Floyd, 2004), and with this burden, they are more likely to have less income and live in poverty. As care needs often translate into reduced maternal employment (Emerson, 2004; Parish et al., 2004), many caregivers endure forced unemployment or reduce their hours of work to care for their children with disabilities. As families often live on single income of a parent, extra and/or added financial expenditure required for caring for their CDD adds burden on caregivers, increasing their stress level and hence, the burden may ultimately lower their LS.

Using the large-scale national data on individuals with DD and their caregivers, this study provides several important theoretical implications. The results of this study show that the caregivers’ appraised stressors (i.e., caregiving stress and perceived financial burden) have more powerful influence on their level of LS, rather than the objective stressor (i.e., the amount of time demands of caring). This result provided additional empirical evidence to the stress theories. It well exhibited the important role of cognitive appraisal in determining one’s situation as stressful or manageable. In addition, the data employed was the only one that was large-scale and nationally representative of the whole population of people with DD conducted by the Korean government. The findings deducted from this data thereby possess a high probability of reliability and validity. These results will help researchers understand the associations among the three care-related stressors and LS among the caregivers of CDD. Furthermore, this study attempted to examine the links between child’s disability-causing hardships and the caregivers’ well-being. As the time demands of caring, caregiving stress, and perceived financial burden in relation to caregivers’ LS have seldom been studied in previous literature, the findings of the study illuminate the importance of understanding the caregivers’ LS and its predictors. This study also has a crucial practical implication. The significance of the caregiver’s appraised stressors on their LS implies that psychological supports are required for the caregivers of CDD along with financial or childcare assistance. In South Korea, most government providing disability-related services are targeting the objective situations of CDD (e.g., financial support for education, health-care services, and rehabilitation, and housework services). However, the caregivers of CDD report high level of depression, care burden, and stress compared to those of children without a disability (Cho et al., 2011; Seltzer, Greenberg, Floyd, & Hong, 2004; Singer, 2006). Recently, Korean government is making attempts to support the caregivers’ psychological and emotional health. In June 2013, MOHW nationally initiated psychological and emotional counseling service as a pilot project for parents of CDD. This pilot service aimed to provide intensive psychological and emotional counseling in order to alleviate their negative psychological and emotional status, and eventually enhance family functioning. It is expected that these counseling and psychological therapy for the caregivers will have positive influence on decreasing their level of stress and depression or improving their psychological well-being and self-esteem (Kim & Son, 2011; Kwak & Jeong, 2010). Unfortunately, this counseling service is, at current state, limited to parents of CDD below the average national income level and requires the user’s out-of-pocket costs ranging 0 to 40 thousand Korean currency (approximately, at maximum of 39 US dollars) based on the means test. This barrier should be gradually lowered in order to maximize the users who are in need of psychological and emotional support.

Despite the contributions of this study, several limitations and suggestions must be acknowledged for future research. First, this study is a cross-sectional study which warrants caution in interpreting the results. Future studies using longitudinal data may provide more accurate information on the causal relationship of the variables. Second, the heterogeneity of the study sample should be taken into great consideration. Although, in general, life quality of families caring for a person with a disability is relatively low, this does not mean that all families have low QoL compromised by caring for a family member with a disability (Cummins, 2005). Thus, the degree and types of disabilities can be important factors to be considered. Future studies need to examine the relationships among the care-related stressors and LS separately by the severity of disability, disability types, and additional problematic behaviors of CDD. Third, future studies should consider including parents of children without disability as a reference group. As the data used in this study specifies the sample to the individuals with DD, it is difficult to conclude whether the caregivers’ LS is indeed low as there is no comparison group.

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