Caring, Employment, and Quality of Life: Comparison of Employed and Nonemployed Mothers of Adults With Intellectual Disability

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Abstract
The effects of caregiving on mothers of adults with intellectual disability was examined by determining whether there are differences in quality of life and related factors between mothers with different employment status. Study participants were 302 working-age mothers who had adult children with intellectual disability based on the 2008 census survey on intellectual disability carried out in Hsinchu, City, Taiwan. Results revealed that nonemployed mothers are more likely to have a lower level of health status, including the WHOQOL Physical Health domain, than are mothers employed fulltime. Multiple regression analysis showed that mothers’ quality of life was significantly determined by the availability of a person with whom they could share care work, family income, social support, and employment status.

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In the last 10 years, Western literature in the field of social science has focused attention on the concept of the work–family interface, including the gender issue (Barnett, 2002; Barnett & Hyde, 2001; Green, Renfrew, & Curtis, 2000; Kinnunen, Feldt, Geurts, & Pulkkinen, 2006; Kröger, 2004, 2005; Pavalko & Henderson, 2006; Voydanoff, 2005; Yeandle, Bennett, Buckner, Shipton, & Suokas, 2006; Yeandle, Wigfield, Crompton, & Dennett, 2002). Without doubt, there are some family caregivers of people with intellectual disability who leave their paid work due to a conflict between work and family caregiving (Baldwin, 1985; Freedman, Litchfield, & Warfield, 1995; Seltzer, Schupf, & Wu, 2001). In relation to this, the family member with intellectual disability is more likely than the other adult children to continue living with the family caregivers throughout adulthood (Chou, Lin, Chang, & Schalock, 2007; McConkey, 2005). As a result, these life-long caregivers are juggling between paid work and their caregiving responsibilities for a much longer time than other types of caregivers, such as those of young typically developing children.

In Taiwan, the vast majority of people with intellectual disability (95%) are provided with lifelong care by their natural families, which can last up to 5 decades (Department of Statistics, Ministry of Interior, Taiwan, Republic of China, 2007). These informal, unpaid caregivers are usually
female and the person’s mother (Chou et al., 2007; Department of Statistics, 2007). As in Western societies (Heller, Hsieh, & Rowitz, 1997; Olsson & Hwang, 2001), a Taiwanese mother of a child with disabilities has more physical and psychological caregiving problems than does a father of a child with disabilities (Chou & Palley, 1998). In addition, compared to mothers who have a typically developing child, these mothers encounter many more problems with their family dynamic and outside family support systems. including coping with the negative attitudes of people outside the immediate family group (Chou, 1985; Shu, 2002; Wang, 1994; Wu, 2006). Mothers’ stress or difficulties also include limited resources to take good care of their child with disabilities and worry about the child’s future care when they are no longer able to provide it (Chou, 1996; Chou, Lee, Lin, & Kröger, 2009; Lin, 1994; Tsau & Chuang, 2007). In addition, Chou et al. (2007) published findings consistent with those of Parish, Seltzer, Greenberg, and Floyd (2004), namely, that family caregivers of adults with intellectual disability have lower rates of employment than do other citizens of working age. In general, the Taiwanese literature has only emphasized the issues of family caregivers’ burden or stress, and there has been little research conducted on the choice between work and caregiving that is often made by these family caregivers.

Work–Family Interface and Gender

The work–family interface has been studied in detail over the past 3 decades. Work–family conflict has been disaggregated into two components: work interfering with family and family interfering with work (Gutek, Searle, & Klepa, 1991). Overall, the interface between work and family can vary from positive to negative (Barnett, 2002). In some cases adding a worker role might be beneficial to both women and the family. For instance, a mother’s employment might have a positive effect on marital quality through increased family income (Ross & Huber, 1985). Positive work-to-family spillover has been correlated with well-being at work and general well-being (Kinnunen et al., 2006). Young and Grundy (2008) found that although these dual roles may be perceived as a burden by some caregivers, others reported that they would like to continue combining caregiving and employment.

According to gender role theorists (Bem, 1993; Pleck, 1977), women are more likely than men to see the family role as part of their social identity. Based on the demand hypothesis, as more time is demanded by the labor market, less time is available for caregiving. On the other hand, the greater the amount of caregiving needed at home, the greater the time that will be invested in the family (Lippe, Jager, & Kops, 2003). In addition to the above balance, from the resource perspective, social support can act as a buffer to these effects. In other words, adding the worker role might be beneficial to women, and multiple roles might increase opportunities for social support, which, in turn, increase well-being (Barnett & Hyde, 2001). Schields (2004) indicated that emotional support might moderate the association between stress and psychological well-being, particularly over the long-term among women. Several researchers have found strong evidence that work–family conflict is associated with various indicators of well-being (Allen, Herst, Bruck, & Sutton, 2000; Brough, O’Driscoll, & Kalliath, 2005; Carlson, Kacmar, & Williams, 2000; Evandrou & Glaser, 2004; Kinnunen, Geurts, & Mauno, 2004; Konrad & Mangel, 2000; Kossek & Ozeki, 1998; Perrone, 2000). Nevertheless, the near invisibility of the conflict between unpaid caregiving and work remains relatively unexplored, and this is especially true among mothers who need to care for an adult child with intellectual disability for many years.

Life-Long Caregiving, Employment, and Well-Being Among Mothers of People With Intellectual Disability

Having a child with disabilities has been shown to have a critical effect on women’s employment (Kuhlthau & Perrin, 2001; Parish et al., 2004; Shearn & Todd, 2000; Thyen, Kuhlthau, & Perrin, 1999), but other factors, such as age, education, marital status, and income level, have also been found to be significant factors associated with women’s involvement in the labor force (Baldwin, 1985; Lippe et al., 2003; Organization for Economic Cooperation and Development, 2001). Specifically, some caregivers might leave their paid work because they do not have enough support for their long-term care provision (Einam & Cuskelly, 2002; Shearn & Todd, 2000; Thyen et al., 1999; Todd & Shearn, 1996). Whether these two groups of mothers with different employment
status have diverse social demographic backgrounds and context has rarely been explored.

Several studies (Heller, Caldwell, & Factor, 2007; Parish et al., 2004; Shearn & Todd, 2000; Thyen et al., 1999; Walker, Ortiz-Valdes, & Newbrough, 1989) have indicated that caregiving has a negative impact not only on maternal employment, but also on family income in the form of low income, low savings, isolation, and mental health; this is because mothers often have to give up or cut back on employment in order to care for a child with disabilities. Although characteristics of the child have been found to be associated with lower levels of maternal psychological well-being (Heller et al., 2007), Thyen et al. (1999) and Walker et al. (1989) found that remaining employed buffers against the negative effects of home care on maternal mental health and depression. Many investigators have discussed the quality of life among family caregivers or parents of people with intellectual disability (Brown, Anand, Fung, Isaacs, & Baum, 2003; Browne & Bramston, 1998; Chou et al., 2007; Jokinen & Brown, 2005; Mactavish, Mackay, Iwasaki, & Betteridge, 2007; Poston et al., 2003; Summers et al., 2005; Walden, Pistrang, & Joyce, 2000). The factors associated with family-centered quality of life are generally reported to be associated with the severity level of the disability (Chou et al., 2007; Mactavish et al., 2007; Walden et al., 2000), the family income (Chou et al., 2007; Mactavish et al., 2007), the caregiver’s relationship with the adult child (Heller et al., 1997), and caregiver’s age and health (Chou et al., 2007; Mactavish et al., 2007). Nonetheless, there have been very few studies in which researchers focused on the effect of labor force involvement on quality of life among the caregivers of people with intellectual disability.

A review of the previous literature shows that employed mothers of adults with intellectual disability may have better well-being than nonemployed mothers; nonetheless, some research shows that the involvement of women in several roles might have a negative effect on well-being in some circumstances. However, there is a lack of research comparing employed and nonemployed mothers of this group in terms of quality of life, including whether their various individual characteristics are also related to their quality of life. Thus, in this research on mothers of adults with intellectual disability, we tested three hypotheses. First, there would be significant differences among the fulltime employed, the parttime employed, and the nonemployed mothers in terms of their social demographic context, health status, level of social support, and quality of life. Second, the mothers’ quality of life would be significantly associated with their involvement in the labor force, namely, being employed or being nonemployed, the care demands of the adult child with intellectual disability, and their individual social demographic data. Third, the factors associated with maternal quality of life would be between the employed and nonemployed groups.

A person’s work–life balance has become one of the major concerns in industrialized countries. In general, Western and Taiwanese researchers have found that family care has a negative impact on unpaid caregivers. The current study is the first one in which the relationships between gender, work, and family among working mothers of adults with intellectual disability is explored. The present study will be helpful to policymakers, practitioners, and researchers who need to be aware of this issue and who can help with the development of appropriate supportive welfare and labor policies. Such development should aid in greater compatibility between paid employment and family life among these life-long caregivers.

Method

Data Collection

In this study a working age mother was defined as the female primary family caregiver of an adult with intellectual disability who met all of the following criteria: (a) she was the person most responsible for the ongoing caregiving of the adult with intellectual disability who was at least 18 years of age, and (b) she was the mother of the adult with intellectual disability and she was younger than 65 years. Based on Taiwan civil law (Article 1122), the word family means family members including all relatives who live together and share a mutual life. The definition of family in terms of welfare benefit in Taiwan is identified by the welfare laws and includes family members who share the same household. Thus, in this context, family members may be spouses, parents, children, grandparents, and siblings; the family might consist of either a nuclear family or an extended family, namely, one where more than two generations live together in the same household.
We conducted a census interview survey on all primary family caregivers of adults with intellectual disability and with multiple disabilities in addition to intellectual disability who were at least 18 years of age and living with family caregivers in Hsinchu City. These persons, who formed the initial study population, were asked to participate in the study. Of the 934 adults with intellectual disability or multiple disabilities in the original lists who were over 18 years of age and living with family caregivers, 47 were not living at the correct address and 91 declined to participate. By the end of participant selection, 796 family primary caregivers of adults with intellectual disability or multiple disabilities completed the interviews, which is a net response rate of 85.2%. Among this group, 548 (68.8%) of these family primary caregivers were female, 403 (50.6%) were mothers of the adults with intellectual disability or multiple disabilities, and 302 (37.9%) were mothers who were younger than 65. These 302 working age mothers then became the participants in the current study.

We made initial contact by a telephone call, at which time informed consent for the interview was obtained from the primary family caregiver; this was followed by a formal invitation letter, which was sent by the city government. Structured interviews were then conducted at the participants’ home between December 2007 and April 2008 by 1 of 14 trained interviewers, who read through the questionnaire and recorded the answer to each question. The interviewers consisted of 4 college students who were majoring in social work and special education and 10 practitioners of special education or homecare from volunteer organizations in the city. All had completed 5 hours of interviewer training. Ethical approval to conduct the study was obtained from the research ethics board of the National Yang-Ming University.

Variables and Measures

The survey packet contained the World Health Organization Quality of Life (WHO-QOL)-BREF Taiwan version scale—hereafter called the WHOQOL scale (Yao, Chung, Yu, & Wang, 2002), the Social Support Scale (Dunst, Jenkins, & Trivette, 1984), the EQ-5D Scale (U.S. Valuation, 2005), and a questionnaire to collect the caregiver characteristics, including employment status. Furthermore, we determined the caregiving needs of the adult child with intellectual disability by using the Activities of Daily Life—ADL (Mahoney & Barthel, 1965) and Instrumental Activities of Daily Life—IADL (Lawton & Brody, 1969) scales. All questions, including the adult’s characteristics and the ADL/IADL scales were answered by every participant.

Measurement of the adults’ variables. The adult’s age was coded as a continuous variable, with a higher score indicating that the person was older. Adult’s care demands refers to his or her behavioral functioning in terms of the ADL and IADL scales, and these were based on the total scores calculated from the Barthel Index (Mahoney & Barthel, 1965) and the Philadelphia Lawton and Brody Index (Lawton & Brody, 1969). A higher score indicates better functioning. The internal reliability (α) of these scales was high (.94 and .86, respectively, for ADL and IADL) in this study.

Assessment of the caregivers’ employment status. To identify the participants’ employment status, caregivers were asked about whether they had fulltime employment, parttime employment, never were employed, or were not currently employed due to caregiving work or retirement. Those participants who formed the employed group (including both full- and parttime employees) were coded as 1, and those who were not employed were coded as 0 (never been employed, not employed due to caregiver work or retirement).

Measurement of the caregivers’ variables. We asked the caregivers about their age, marital status, number of years education completed, whether they had a substitute person to take care of adult child with intellectual disability, their health, and level of social support. The caregiver’s marital status was coded as married (including cohabitation) or single (including widowed and divorced). Whether the caregiver had a substitute person taking care of her adult child with intellectual disability was coded yes or no (no = 1, yes = 0). Caregiver’s age and years of education received were coded as interval variables. General health status was measured by the EQ-5D Taiwanese version, which contains five items that measure five dimensions, namely, Mobility, SelfCare, Usual Activities, Pain/Discomfort, and Anxiety/Depression; each of these dimensions are coded with an ordinal number, ranging from 1 (no problems) to 3 (extreme problems) (U.S. Valua-
tion, 2005). A higher score indicates a lower health status level. The Taiwanese EQ-5D instrument appears to be a moderately valid and reliable tool for measuring the health status of the general population in Taiwan (Chang et al., 2007). However, the Cronbach’s alpha was .59 among the 302 mothers in this study. In this context, the EQ-5D was removed from the regression analysis because its five items were very similar to the Physical and Psychological domains of the WHOQOL. The family income used in the regression analysis was coded as five ordinal categories and indicates the total amount of income per month of all family members in the household. A higher score indicates a higher family income.

Measurement of caregiver family social support. Family social support was measured using a translated Chinese version of the Family Support Scale (Dunst et al., 1984); a higher score indicates greater family support. The internal reliability of this instrument yielded a Cronbach’s alpha of .80 in the present study.

Measurement of the use of family support services. We assessed the caregiver’s and the adult’s utilization of five types of family support services, namely, day care, home care, respite care provided at an agency, respite care provided at home, and home nursing care. To determine whether the participants used the services, we asked whether they knew of each of the five types of services (this was coded as yes or no); if the answer was yes to any type of service, they were asked whether they had used that service. If used, the family support service was coded as 1; otherwise, 0. For the analysis, if the participant used any one of the five types of services, it was recoded as 1. Alternatively, if the participants did not use any of the five types of services, it was coded as 0.

Measurement of the caregiver’s quality of life. Caregiver's quality of life was assessed with the WHOQOL scale, which contains 28 items and four domains—Physical, Psychological, Social Relationships, and Environment. A higher score indicates a better quality of life. The original WHOQOL with 26 items was translated into Chinese, and two additional appropriate culture-related items were added by Taiwanese scholars (Yao et al., 2002). These two items were face (i.e., loss of status and self-esteem leading to feeling embarrassed) and food satisfaction. They were added into the domain of Social Relationships and Environment, respectively. The first of the added items asks in Chinese, “How do you feel about saving face and being respected?” There is a famous Chinese saying: “Food is all important to people,” which was the impetus for the second added item, “Do you get enough of the foods that you like to eat?” (Yao et al., 2002). In Taiwan, if families have a member with intellectual disability and define this as an unsuccessful social performance, the families can suffer from stigma and a loss of ancestral face (Chou & Palley, 1998). Thus, we used the Taiwan version of the WHOQOL rather than the original one. The internal reliability of the Taiwan version yielded a Cronbach’s α of .92 for the total scores for the 28 items among the 302 participants (for more details about the scale, see Chou et al., 2007).

Data Analysis
The individual caregiver was the unit of analysis. We analyzed the results using the Statistical Package for Social Sciences (SPSS), Version 17.0. Descriptive statistics were used to explain the distribution of the participants. We utilized ANOVA and a cross-table to determine whether the mothers’ individual characteristics varied in terms of their employment status for the three groups (fulltime employed, parttime employed, and nonemployed). The covariance of the mothers’ quality of life, Health Status, and Social Support domain WHOQOL scores were compared between the three groups. The covariates were the adult’s age, the adult’s ADL, the mother’s age, the mother’s years of education, and the family income. These covariates were selected because they make up the background characteristics by which the three groups may differ (Table 1).

In order to identify factors affecting the mothers’ quality of life, including employment and nonemployment, we conducted a linear regression analysis, with the dependent variable (the level of mothers’ subjective quality of life) constructed as a continuous variable. The independent variables included the adult with intellectual disability’s behavioral functioning in terms of ADL and IADL, the mother’s age, the mother’s education level, the mother’s marital status, the availability of a substitute person to take care of her adult child with intellectual disability, whether the mother used family support services, the mother’s self-reported social support, and the family income.
Results

Participants' Characteristics and a Group Comparison

Of the 302 working age mothers, 37.4% were employed fulltime, 16.2%, parttime; and 46.4% were not employed (Table 1). The average age of the adults with intellectual disability was 26.1 years ($SD = 6.1$); the average age of the mothers was 52.3 years ($SD = 5.9$). The majority of the mothers were married and had a substitute person to take care of the adult child with intellectual disability.

As can be seen in Table 2, there were significant differences between the groups in

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>All participants ($N=302$)</th>
<th>Employment status</th>
<th>$F$ (post hoc)</th>
<th>$\chi^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult with ID$^a$</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age</td>
<td>26.10</td>
<td>24.95</td>
<td>24.73</td>
<td>27.51</td>
</tr>
<tr>
<td>Mean ADL$^b$</td>
<td>90.50</td>
<td>94.96</td>
<td>87.45</td>
<td>87.89</td>
</tr>
<tr>
<td>Mean IADL$^c$</td>
<td>12.10</td>
<td>13.09</td>
<td>10.49</td>
<td>11.94</td>
</tr>
<tr>
<td>Mother</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Mean age | 52.30 | 50.80 | 51.40 | 53.80 | 8.79*** (3>1***)
| Mean years of education | 8.10 | 8.70 | 8.40 | 7.50 | 3.58* (1>3*) |
| Marital status (% with partner) | 77.80 | 77.00 | 79.60 | 77.90 | 0.13 |
| Availability of a substitute person to care for adult with ID (% yes) | 65.60 | 65.50 | 71.40 | 63.60 | 0.99 |
| Use of any family support service (% yes) | 30.50 | 31.00 | 32.70 | 29.30 | 0.22 |
| Family income (%) NT$^d$ | | | | |
| <$20,000 | 21.20 | 13.30 | 20.40 | 27.90 | 5.68* (3>1*) |
| $20,001–40,000 | 44.00 | 45.10 | 36.70 | 45.70 | 12.92* |
| $40,001–60,000 | 21.90 | 23.00 | 36.70 | 15.70 | |
| $60,001–80,000 | 6.30 | 9.70 | 4.10 | 4.30 | |
| >$80,000 | 6.60 | 8.80 | 2.00 | 6.40 | |
| Mother health | 6.10 | 5.80 | 6.10 | 6.30 | 5.68* (3>1*) |
| Mean mother social support | 18.30 | 19.60 | 18.90 | 17.10 | 3.51* (1>3*) |
| Mean mother QOL$^e$ | 92.40 | 95.00 | 94.00 | 89.80 | 6.44* (1>3*) |
| Domain$^f$ | | | | |
| Physical Health | 14.20 | 14.70 | 14.80 | 13.50 | 10.92*** (1>3***; 2>3***) |
| Psychological | 12.70 | 13.00 | 12.90 | 12.40 | 3.51* (1>3*) |
| Social Relationships | 13.60 | 13.80 | 13.60 | 13.50 | 0.26 |
| Environment | 12.80 | 13.10 | 12.90 | 12.50 | 0.75 |

$^a$Intellectual disability. $^b$Activities of daily living. $^c$Instrumental activities of daily living. $^d$New Taiwan dollar; 1 U.S. dollar = 33 Taiwan dollars. $^e$Quality of life. $^f$WHOQoL domains.

*p<.05. **p<.01. ***p<.001.
terms of the adults’ age, level of ADL, mother age, years of education, family income, self-reported health, social support, and overall quality of life, including the Physical and Psychological Health domains of WHOQOL. However, a statistical comparison revealed no significant differences between the three groups for caregiver marital status, whether there was a substitute person to take care of the adult child with intellectual disability, and whether there was use of family support services.

Table 2 indicates that the health status and the Physical Health domain of the WHOQOL scale among the nonemployed mothers were still lower than those of mothers in the two employed groups after controlling for the adults’ and mothers’ individual social demographic variables (adult age, adult level of ADL, mother age, mother year of education, and family income).

Factors Associated With Mothers’ Quality of Life

We used linear multiple regression to identify predictors for the level of quality of life among the participants. As can be seen in Table 3, in Model 1, for mothers with fulltime or parttime employment, whether there was a substitute person to care for the adult with intellectual disability, family income, and social support of the mothers were significantly associated with their level of quality of life. In Model 2, using the same nine independent variables, we found these three factors were significantly associated with the level of quality of life among the nonemployed mothers; however, they were at different magnitudes. The absence of a substitute caregiver, for example, would reduce the quality of life score by 7.3 compared with those who have a substitute caregiver for the nonemployed group. This is higher compared with the magnitude for the employed group. The effect of family income and social support, however, were lower for the nonemployed group, which had another factor that was significantly associated with quality of life: the adult’s level of IADL, $B = 0.57, p < .01$. Model 3 is the full sample regression, with mother employment status (employed = 1) as an independent variable. The results showed that the state of having a substitute person to care for the adult with intellectual disability, family income, and social support remained statistically significant, and the employ-
Table 3. Multiple Linear Regression Analysis for Factors Associated With Mothers’ Level of Quality of Life

<table>
<thead>
<tr>
<th>Independent variable</th>
<th>Model 1 Employed mothers&lt;sup&gt;a&lt;/sup&gt; (n=162)</th>
<th>Model 2 Nonemployed mothers&lt;sup&gt;b&lt;/sup&gt; (n=140)</th>
<th>Model 3 All nonelderly mothers&lt;sup&gt;c&lt;/sup&gt; (n=302)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult ADL</td>
<td>.06</td>
<td>-.06</td>
<td>.00</td>
</tr>
<tr>
<td>Adult IADL</td>
<td>-.04</td>
<td>.07</td>
<td>.20</td>
</tr>
<tr>
<td>Mother age</td>
<td>-.21</td>
<td>.27</td>
<td>.28</td>
</tr>
<tr>
<td>Mother education</td>
<td>.22</td>
<td>.27</td>
<td>.28</td>
</tr>
<tr>
<td>Mother marital status (single)</td>
<td>-3.77</td>
<td>1.55</td>
<td>1.39</td>
</tr>
<tr>
<td>Availability of a substitute person to care for the adult with ID (no)</td>
<td>-4.15</td>
<td>-7.31</td>
<td>-4.86</td>
</tr>
<tr>
<td>Family income</td>
<td>3.10</td>
<td>1.98</td>
<td>2.81</td>
</tr>
<tr>
<td>Mother social support</td>
<td>.35</td>
<td>.27</td>
<td>.29</td>
</tr>
<tr>
<td>Whether use family support services (yes)</td>
<td>-1.24</td>
<td>1.14</td>
<td>-.56</td>
</tr>
<tr>
<td>Mother employment status (yes)</td>
<td></td>
<td>2.74</td>
<td>.11</td>
</tr>
</tbody>
</table>

| Adjusted $R^2$                                            | .27                                        | .22                                             | .25                                             |

<sup>a</sup>Nine independent variables. <sup>b</sup>Nine independent variables. <sup>c</sup>Ten independent variables; whether mothers were employed was included.

*p < .05, **p < .01, ***p < .001.
Discussion

When we have referred to the concept of work–family reconciliation including the gender issue, our intent in the present study was to explore who are the employed and nonemployed among working age mothers of adults with intellectual disability and to examine the effect that care work has on these mothers in terms of, for example, their quality of life. Our findings suggest that working age mothers of adults with intellectual disability who combine both their paid work and care responsibilities are generally younger, are better educated, have a better family income, are healthier, have a higher level of social support, and have higher scores for the Physical Health and Psychological domains of the WHOQOL scale; furthermore, their adult children have a higher level of ADL (as shown in Table 1). This is partially consistent with results of Thyen et al. (1999), who found that employed caregivers had higher levels of family support and better health than those who were not employed. Meanwhile, consistent with previous studies (Baldwin, 1985; Lippe et al., 2003; Organization for Economic Cooperation and Development, 2001), our study revealed that the mother’s age, the adult child’s ADL, and the family income were significantly associated with the mothers’ involvement in employment. These factors may be associated with difficulties in, for example, finding an appropriate way of combining work and care, particularly when the mother has a lower social status (Baldwin, 1985; Yeandle et al., 2006). It also supports the hypothesis of Lippe et al. (2003), who suggested that the greater the care needed by the adult child with intellectual disability, the more time will be invested in the caregiving work by the mothers, and this will inhibit the mothers’ involvement in employment. It is possible that when informal caregiving interferes with the caregivers’ employment, then it will inevitably affect the caregiver’s income and employment-related benefits and increase noneconomic costs (Fast, Williamson, & Keating, 1999), which may result in declines in certain aspects of the caregiver’s quality of life, such as their physical and psychological well-being. However, the true underlying mechanism remains to be investigated.

There were no significant differences between the groups in terms of caregiver marital status, whether they had a substitute person to take care of their adult child with intellectual disability, or whether they used family support services. This implies that these working age mothers, regardless of employment status, were mostly married, which resulted in a substitute person being available when needed; in addition, the presence of a husband and his support might have an effect on their use of formal family support services. Furthermore, we found that parttime employed mothers did not differ significantly from either their fulltime or nonemployed counterparts, the exception being the Physical Health domain of the WHOQOL scale, where a significant difference was found between parttime employed and nonemployed mothers. From Table 1, it can be seen that only 49 (16.2%) of the 302 working-age mothers in our sample were employed parttime and that the average scores for the various measures among these mothers were quite similar in distribution to the other two groups. It will be necessary in the future to find out who these parttime employed mothers are in terms of whether they have been involved in fulltime employment previously or whether they are more similar to the nonemployed mothers and have not found it easy to enter the fulltime labor force.

It is worthwhile to point out that the mean scores for all four domains of the WHOQOL scale among the working-age mother caregivers, no matter whether they were involved in the labor force, were all lower than for the general Taiwanese population (Yao & WHOQOL Taiwan version Development Group, 2004), which suggests that developers of related polices and services need to be concerned about the quality of life of all these mothers, both the employed and nonemployed. The differences in the mothers’ social support, the Psychological domain of the WHOQOL scale, and the overall quality of life decreased and became insignificant across the three groups after we controlled for the adults’ and mothers’ social demographic data (see Table 2), showing that the differences in mothers’ social support, their WHOQOL scale Psychological domain score of quality of life, and the overall quality of life between the employment groups may be explained by the adult’s age, the adult’s level of ADL, the mother’s age, the mother’s years of education, and the family income.
However, health status and the Physical Health domain of the WHOQOL scale among the mothers who combined paid work and care responsibilities remained better than that among nonemployed mothers who were caregivers even after we controlled for demographics. This may imply that more employed caregivers need to be healthy if they are to have dual roles consisting of both paid work and unpaid caregiving. On the other hand, it is possible that the mothers’ involvement in employment might have resulted in positive effects on their lifelong caregiving work compared with their nonemployed counterparts. For instance, previous intellectual disability studies (Heller et al., 2007; Parish et al., 2004; Shearn & Todd, 2000; Thyen et al., 1999; Walker & Hyde, 1989) and women’s studies (Barnett & Hyde, 2001) have indicated that a role as a worker can be beneficial to caregivers and women. However, the presence of a causal effect between labor force involvement and mothers’ health will have to be confirmed by further research. One possibility is that mothers who are not employed might have given up their paid work involuntarily, perhaps due to age, their own health status, or their adult child’s health status.

In addition, we used multiple regression to identify the predictors of level of quality of life among the participants. As shown in Table 3, the results of Models 1 and 2 are consistent with the results of Model 3 and imply that regardless of whether the mothers are employed, having a person to share care work, the family’s financial condition, and the mother’s social support were the significant factors associated with quality of life. This finding is consistent with previous Western and Taiwanese studies in which investigators examined the family caregivers of persons with intellectual disability (Chou et al., 2007; Kou & Wang, 2006; Mactavish et al., 2007). Furthermore, our results suggest that nonemployed mothers, the level of IADL of their adult child with intellectual disability is also a significant predictor of their quality of life. This is consistent with findings from a previous Taiwanese empirical study (Chou et al., 2007). In addition, other than those three significant variables from the three models discussed previously, we found that employment status was significantly related to quality of life among both employed and nonemployed mothers (as shown in Model 3 in Table 3). For example, employed mothers were more likely to report a higher level of quality of life than were their nonemployed counterparts, which is consistent with the findings in Table 2 as discussed previously and one recent Taiwanese study, in which Chou, Kröger, Chiao, and Fu (2009) showed that nonemployed family caregivers had a lower level of health status and poorer family life satisfaction than did their employed counterparts, which implies that having paid work improves the well-being of these mother caregivers, consistent with previous Western literature (Barnett & Hyde, 2001; Kinnunen et al., 2006; Robinson & Spite, 1992).

To sum up, based on the multiple regression analyses and the discussion above, these findings suggest that when trying to improve the quality of life of both employed and nonemployed mothers, their social support, availability of a person to share care responsibility, and family income cannot be ignored. This seems to be especially true in terms of instrumental support for caregiving needs. Meanwhile, it is necessary for policymakers to pay attention to nonemployed mothers whose adult children have a lower level of functioning in terms of IADL. Finally, the findings suggest that there is a need for public policies to support women caregivers involved in the labor force.

In addition, we note that mothers’ use of the family support services provided by the local government was not significantly related to their level of quality of life. Based on Taiwan’s disability welfare legislation, local authorities are required to provide formal social services for people with disabilities, including family support services. However, the number of persons with disabilities using such services is very limited (Chou et al., 2008; Department of Statistics, 2007).

Implications

First, the results of the current study suggest that lifelong caregiving mothers who are now employed and who have been able to adjust to paid work and family care must not be ignored in terms of welfare and employment policies. Second, the related policymakers also need to consider how it is possible to promote well-being among this group of working-age lifelong caregiving mothers. In terms of improving the well-being of these mothers, issues of health; family income; and wide ranging family support services, particularly those providing instrumental support; and finding a person to share the care work need to be promoted and supported. Any approach needs to target those mothers who are not able to be involved in the labor force, especially those mothers with a low...
level of family income, who have poorer social support, who do not have a person to share the care work, and whose adult child has a low level of IADL. Third, the results also confirm a positive relationship between the mothers’ employment status and the level of quality of life, suggesting that helping mothers be involved in the labor force can be one strategy for promoting these lifelong mother caregivers’ quality of life. Furthermore, from the gender equality perspective, supporting mothers to have paid work and helping to make their paid work and care responsibilities compatible should be of concern in terms of both labor and social welfare policies. We also recommend that the availability and use of service systems be considered in order to develop strategies that will increase the use of family support services.

**Limitations**

Some limitations of the present study need to be acknowledged. First, we did not examine work-related factors, such as the characteristics of the mothers’ work, their working hours, the positions of the participants, and their level of perceived work stress, although we did collect the participants’ caregiving-related variables, such as the hours of caregiving per day and their adult child’s ADL and IADL. We suggest that in a future study investigators should add such family caregiver employment-related data for the employed mothers to the predictive models. In such an approach researchers could use the work–family conflict interface or the working age mothers’ well-being as dependent variables (Barnett, 2002; Voydanoff, 2002). Second, in our cross-sectional study, we found that the participants’ individual characteristics were significantly associated with the mothers’ employment status. However, the results are not able to reveal a causal relationship between the mothers’ individual variables and their involvement in the labor force. Moreover, we were not able to represent variations in the participants’ experience over time, such as the different parts of the life cycle that involved the mother and the adult child with intellectual disability. Thus, we are not able to show the direction of the association between the predictive variables (mothers’ and their adult child’s characteristics) and the dependent variable (quality of life). This suggests that a longitudinal study to answer this question would be beneficial. Finally, although participants were recruited through census survey data in Hsinchu City and all potential mothers were involved, the findings may not be representative of wider samples of working-age mothers from other cities and counties. Furthermore, even though our samples may be representative of the general working-age mothers of adults with intellectual disability, there is still a risk that there are differences between those who participated in the survey and those who did not. Thus, the generalizability of findings from this study is limited because participation in the survey was voluntary.

In spite of the above limitations, as far as we know, this is the first study conducted in Taiwan in which researchers have investigated the relationship between paid work and family care responsibilities among working-age mothers who have an adult child with intellectual disability and that includes an examination of the association between the mother’s employment status and the mother’s well-being. We hope that, with increasing attention being given to well-being and involvement in the labor force of these lifelong caregiving mothers, our results will highlight the needs for social support, family income, and a person to share caregiving with these working-age mothers, both employed and nonemployed. The present study adds to the limited literature that is available on identified associations among lifelong caregivers between paid work and family care responsibilities, including gender concerns.

In conclusion, these results show that nonemployed mothers of adults with intellectual disability are from a more disadvantaged social context when compared with their employed counterparts. However, all working-age mothers who cared for an adult child with intellectual disability displayed a lower level of quality of life than did mothers in the general Taiwanese population, suggesting that quality of life among mothers of an adult child with intellectual disability in Taiwan needs to be of concern. Our findings also suggest that the working-age mothers’ personal and family characteristics are strongly associated with their quality of life, including their employment status. This study also indicates that financial support and caregiving support among these groups of working-age mothers are very necessary, including supporting their involvement in the labor force.

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