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**Topic: Caring, employment and QOL: a comparison of employed  
and non-employed mothers of adults with ID**

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# **Caring, employment and QOL: A comparison of employed and non-employed mothers of adults with ID**

## **ABSTRACT**

**Background** Informal unpaid carers for people with ID are usually female and mothers. Recent Western literature has focused attention on the concept of work-family reconciliation including the gender issue. Without doubt, there are mothers of people with ID who leave their paid work due to the conflict between work and family care-giving. We examine the effects of care work on full-time employed, part-time employed and non-employed mothers by studying whether there are differences between these three groups in terms of social demographic context, quality of life, various factors related to their involvement in labor force and their QOL.

**Materials and Methods** We use data from the 2008 census survey on ID in Hsin-Chu City, Taiwan that included the primary family carers of 796 adults (aged 18 or older) with ID who were living with their families. In total, 302 of them were the adults' mothers and were of working age (younger than 65). These 302 mother carers became our study population. The survey package contained standardized scales and collected carer health, social support level, QOL, use of family support services and the characteristic data.

**Results** It was found that 37.4% of the mothers of working age were involved in full-time employment, 16.2% of them were involved in part-time employment and 46.4% were non-employed. The statistics revealed that, compared to their employed counterparts, the non-employed mothers were older, had older adult children, had children with a lower level of ADL, had received less years of education, had a lower level of health status, had a lower level of social support, and were more likely to be from a low income family. Logistic regression analysis showed that the factors that

are significantly related to the mothers' employment status were the adult child's functioning in terms of ADL, the mother's age, and the family income. Compared with the Taiwanese population in general, the mean QOL score for the mothers in all three of these three groups were lower for all the four domains assessed (physical, psychological, social relations and environment). When comparing between these three groups, the mean score for the overall QOL and for each domain (with the exception of the domain of social relationships) were all significantly lower among the non-employed mothers than among the full-timely employed mothers.

Surprisingly, after acknowledging the effect of health status, family income and social support of the participants, logistic regression analysis did not reveal that the mothers' employment status was a significant predictor of the working age mothers' quality of life. We also found that the mothers' involvement in employment was determined by their age, adult child's ADL and family income.

**Conclusions** The present study is a start in addressing the issue of paid work and unpaid work among mothers of people with ID in Taiwanese society. Perhaps these results can become a benchmark for similar measurements carried out by women's movement. These results may then help to frame policy efforts related to the current advocacy for the creation of a supportive environment for lifelong woman carers.

**Keywords:** intellectual disabilities, paid work, mother, quality of life, carer, Taiwan

## **Introduction**

Recent Western literature has focused attention on the concept of work-family including the gender issue (Voydanoff, 2005; Barnett & Hyde, 2001; Barnett, 2002; Kinnunen, Feldt, Geurts, & Pulkkinen, 2006; Kroger, 2004, 2005; Yeandle et al., 2002, Yeandle et al., 2006; Green, Renfrew, & Curtis, 2000; Pavalko & Henderson, 2006). Without doubt, there are some family carers of people with ID who leave their paid work due to a conflict between work and family care-giving (Baldwin, 1985; Heck & Makuc, 2000; Seltzer et al., 2001; Chou et al., 2007a; Freedman et al., 1995). This is particularly true for single carers, who have been found to be more likely to quit employment, compared with mothers in two-parent families (Thyen, Kuhlthau, & Perrin, 1999). In relation to this, the family member with ID is more likely than the other adult children to continue living with the family carers throughout adulthood.

In Taiwan, for the vast majority of people with ID (95%), life-long care (that can last up to five decades) is provided by their natural families (Department of Statistics, Ministry of Interior, ROC, 2007). These informal unpaid care-givers for people with ID are usually female and the person's mother (Chou et al., 2007a; Department of Statistics, Ministry of Interior, ROC, 2007). However, little research has been conducted into the choice between work and care-giving made by these family carers of people with ID.

The work-family interface has been studied in detail over the past three decades. Work-family conflict (WFC) has been disaggregated into two components: work interfering with family and family interfering with work (Guttek et al., 1991);

overall, the interface between work and family can vary from positive to negative (Barnett, 2002). Adding a worker role might be beneficial to women (Barnett & Hyde, 2001) and to the family (Ross & Huber, 1985). According to the demand hypothesis, as more time is demanded by the labor market, less time is available for care; on the other hand, the greater the amount of care needed at home, the greater time that will be invested in the family (Lippe et al., 2003). In addition to the above balance, from the resource perspective, social support can act as a buffer to these effects (Barnett & Hyde, 2001).

Having a child with disabilities has been identified as having a critical effect on employment participation among women (Kuhlthau & Perrin, 2001; Parish, Seltzer, Greenberg, & Floyd, 2004; Shearn & Todd, 2000; Thyen et al., 1999), but other factors such as age, education and income level have also been found to be significant factors associated with labor force involvement among women (Baldwin, 1985; Lippe et al., 2003; OECD, 2001). Specifically, some carers might leave their paid work because they do not have enough support for their long-term care-provision (Einam & Cuskelly, 2002; Shearn & Todd, 2000; Todd & Shearn, 1996; Thyen et al., 1999).

Several studies (Heller, Caldwell, & Factor, 2007; Parish et al., 2004; Shearn & Todd, 2000; Thyen et al., 1999; Walker et al., 1989) have indicated that care-giving has a negative impact not only on maternal employment, but also on family income in the form of low income and low savings, isolation and mental health; this is because

mothers often have to give up or cut back on employment to care for a child with disabilities. Although the 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.'s (1989) found that remaining employed buffers against the negative effects of home care on maternal mental health and depression. Many studies have discussed the QOL of family carers or parents (Browne & Bramston, 1998; Brown et al., 2003; Chou et al., 2007; Jokinen & Brown, 2005; Mactavish et al., 2007; Poston et al., 2003; Reilly & Conliffe, 2002; Summers et al., 2005; Walden et al., 2000; Wang et al., 2004). The factors associated with family-centered QOL are generally reported to be the severity of disability (Chou et al., 2007; Mactavish et al., 2007; Walden et al., 2000; Wang et al., 2004), the family income (Chou et al., 2007; Mactavish et al., 2007; Wang et al., 2004), the carer's relationship with the adult (Heller et al., 1997), age (Reilly & Conliffe, 2002) and health (Chou et al., 2007; Mactavish et al., 2007).

In this research, we ask firstly whether there are significant differences among the full time employed, the part time employed and the non-employed mothers in terms of their social demographic context and quality of life including the factors related to their QOL. Secondly, we tried to determine what are the significant factors associated with mothers' QOL and their involvement in labor force, namely being employed or being non-employed. A person's work-life balance has become one of the major concerns in industrialized countries. In general, family care has been found to have a negative impact on unpaid carers by both Western and Taiwanese studies. It is believed that this study is the first one to explore the relationships between gender, work and family among working mothers of adults with ID. The study will be helpful to policy makers, practitioners and researchers who need to be made aware of this issue and who help with the development of appropriate supportive welfare and labor

policies that will create greater compatibility between paid employment and family life among these life-long mother carers.

## **Methods**

### ***Study population and Procedures***

In this study “working age mother” was defined as female primary family carer of an adult with ID who met all following criteria: the person is most responsible for the ongoing care-giving in the family of an the adult with ID who is aged 18 and older, the person is the mother of the adult and the person is aged younger than 65 year.

A census interview survey was conducted on all primary family carers of adults with ID and multiple disabilities in addition to ID aged 18 and older living with family carers in Hsin- Chu City and these persons formed the initial study population who were asked to participate in the study. Of the 934 adults with ID or multiple disabilities and aged over 18 and living with family carers in the original lists, 47 were not living at the correct address and 91 declined to take part in the study. In the end, 796 family primary carers of adults with ID or multiple disabilities completed the interviews and of these. This yielded a net response rate of 85.2%. Among this group, 548 (68.8%) of these family primary carers were female, 403 (50.6%) were mothers of the adults with ID or multiple disabilities, and 302 (37.9%) were the mothers that were age younger than 65. These 302 working aged mothers then became the final study population.

Initial contact was made by a telephone call, at which time informed consent for the interview was obtained from the primary family carers; this was followed by a formal invitation letter sent by the Hsin-Chu City Government. Structured interviews were then conducted at the participants' home between December 2007 and April 2008 by one of 14 trained interviewers, who read through the questionnaire and recorded the answer to each question. The interviewers consisted of four college students who were majoring in social work and special education and ten practitioners of special education or home care from voluntary organizations in Hsin-Chu City. All had completed five hours of interviewer training. Ethical approval to conduct the study was obtained from the research ethics board of the Yang-Ming University.

### ***Variables and measures***

The survey packet contained the WHOQOL-BREF Taiwan version scale, the Social Support Scale, the ED-5Q Scale and a questionnaire to collect the carer characteristics including employment status. Furthermore, the care-giving needs of the adult child with ID were gathered using the activities of daily life (ADL) and instrumental activities of daily life (IADL) scales. All questions, including the adult's characteristics and the ADL/IADL scales were answered by every one of the participants.

***Measurements on the adults' variables.*** The adult's age was coded as a continuous variable with a higher score indicating that the person was older in age. Adult's care demands refer to his/her behavioral functioning in terms of the Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (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 ( $\alpha$ ) of these scales was high (0.94 and 0.86 respectively for ADL and IADL) in this study. For the data analysis in the current study, the adults' ADL and IADL were then converted into nominal variables and categorized into four levels of functioning (profound, severe, moderate, and mild) based on their scores on the two scales (Table 1).

***Assessment of the carers' employment status.*** To identify the participants' employment status, carers were asked about whether they had full-time employment, had part-time employment, had never have been employed, were not employed due to care work or were not employed because of retirement. Those participants who formed the employed group (including both full time and part-time employment) were coded as "1", and those who are not employed were coded as "0" (never been employed, not employed due to care work and not employed because of retirement).

***Measurements of the carers' variables.*** The carers were asked about their own age, marital status, number of years education received, whether they had a substitute person to take care of adult child with ID, their health and their level of social support. The carer's marital status was coded as married (including co-habitation) or single (including widow and divorced) and whether the carer had a substitute person taking care of her adult child with ID (yes/no). Carer age and the number of years of education received were coded as interval variables. Carer general health status was measured by the EQ-5D Chinese version and its alpha was 0.59 among the 302 mothers in this study and 0.72 among all 796 family primary carers. The scale contains five items that measure five dimensions, namely, mobility, self care, usual activities, pain/discomfort, anxiety/depression; each of these were coded by an ordinal number, ranging from 1 (able to) to 3 (not able to) (U.S. Valuation of the EuroQol EQ-5D Health States, December 2005). A higher score indicates a lower level of health status. 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 carer family social support.*** Family social support was measured using a translated Chinese version of the Family Support Scale (FSS) developed by Dunst, Jenkins and Trivette (1984); a higher score indicates greater

family support. The internal reliability of the FSS yielded a Cronbach's alpha of 0.80 in the present study.

***Measurement of the use of family support services.*** The carer's and the adult's utilization of five types of family support services, namely day care, home care, respite care through an agency, respite care at home, and home nursing care. To find out if the participants used the services, we asked whether they knew each of the five types of services (coded as "yes" or "no") and 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, it was coded as "0" if the participants did not use any of the five types of services.

***Measurements of the carer's QOL.*** Carer's quality of life (QOL) was assessed with the WHOQOL-BREF Taiwan version, which contains 28 items and four domains, namely physical, psychological, social relationships and environment (Yao et al. 2002). A higher score indicates a better QOL. The internal reliability of the WHOQOL-BREF Taiwan version yielded a Cronbach's alpha of 0.92 for the total scores of 28 items among the 302 participants of this study (for more details about the scale, see Chou et al., 2007a). The WHOQOL-BREF was used as a nominal variable (beyond or under the mean total score for the WHOQOL-BREF) in the logistic

regression analysis. Specifically in this study we are concerned about the predictive variables of a low level of wellbeing among the participants and therefore we have defined as a “low level of QOL” where the mothers’ subjective QOL was less than the mean QOL score (the mean score for the 302 participants was 92.0). Therefore a “low level of QOL” was less than 92.0(<92) and a score equal to or greater than 92 was classified as a “high level of QOL” (>92.0). This is shown in Table 3.

### ***Data Analysis***

The individual carer was the unit of analysis. The results were analyzed using the Statistical Package for Social Sciences (SPSS), Version 15.0. Descriptive statistics were used to describe the distribution of the study population. ANOVA and a crosstable were used to determine whether the mothers’ individual characteristics and related variables varied in terms of their employment status. In order to identify factors affecting the employed/non-employed status and the mothers’ QOL, we conduct logistic regression analyses. The independent variables included the adult with ID’s behavioral functioning in terms of ADL and IADL, the carer’s age, the carer’s education level, the carer’s marital status, the availability of a substitute person to take care of her adult child with ID, whether she used family support services, the carer’s self-reported health, the carer’s self-reported social support and the family

income. The dependent variables were the low level of participants' subjective quality of life and whether they were employed.

## **Results**

### ***The participants' characteristics and a comparison between the groups***

As can be seen in Table 1, 37.4% of the 302 working age mothers were full-time employed and also the family's primary carer, while 16.2% were part-time employed and 46.4% were non-employed. The average age of the adults with ID was 26.1 years (SD=6.1) and their average ADL and IADL scores were 90.5 and 12.1, respectively. Overall, 47.7% had severe or profound disabilities in IADL, while 10.3 % had severe and profound disability in ADL. The average age of the mothers was 52.3 years (SD=5.9). The majority of them (77.8 %) were married and had a substitute person to take care of the adult child with ID (65.6%).

There were significant differences between the groups in terms of the adults' age ( $p<0.01$ ), level of ADL ( $p<0.05$ ); mother age ( $p<0.001$ ), years of education ( $p<0.05$ ), self-reported health ( $p<0.01$ ), social support ( $p<0.05$ ), quality of life ( $p<0.01$ ) and family income ( $p<0.01$ ). However, statistical comparison revealed no significant differences between the three groups based on three sampling criteria, namely carer marital status, whether there was a substitute person to take care of the adult child with ID and whether there was use of family support services.

### ***Differences in QOL between the groups and a comparison with the general population***

Table 2 indicates that the mean score for the QOL of the mothers in the three groups was lower across all four domains (physical, psychological, social relations and environment) when compared with the Taiwanese population as a whole. There were significant differences between the groups in terms of the mean score for the overall QOL and for each domain with the exception of the domain of social relationships. *Post hoc* tests showed that non-employed mothers had significantly lower levels for the physical health ( $p < 0.001$ ), psychological ( $p < 0.05$ ), and environment ( $p < 0.05$ ) domains compared to full-time employed mothers.

### ***Predictors of mothers' QOL***

Logistic regression was used to identify predictors of a “low level of QOL” (<92 for the WHOQOL-BREF Taiwan version) among the participants. As presented in Table 3, all three models were statistically significant ( $p < 0.001$ ) as indicated by Chi-square tests. In model 1, among the full- and part-timely employed mothers, of the ten independent variables, education ( $p < 0.05$ ), marital status ( $p < 0.05$ ) and self-reported health ( $p < 0.001$ ) of the mothers were significantly associated with their

“low level of QOL”. In model 2, using the same ten independent variables, non-employed mothers’ family income ( $p<0.01$ ), self-reported health ( $p<0.001$ ) and social support ( $p<0.01$ ) were significant predictors of these mothers’ “low level of QO”. In model 3, we added one independent variable, namely mother employment status (employed or non-employed). The results showed that three factors, family income, health and social support of the mothers, were significant predictors of a “low level of QOL” among all working aged mothers including both employed and non-employed.

### ***Predictors of mothers’ involvement in employment***

As shown in Table 4, of the ten independent variables, mothers’ age ( $p<0.01$ ), their adult child’s functioning in ADL ( $p<0.05$ ) and family income ( $p<0.05$ ) were found to be significantly associated with the mothers’ involvement in employment. The mothers’ education, martial status, health, social support, whether there was a substitute person to take care of the adult child with ID, and whether there was use of family support services did not show a significant association with the mothers’ involvement in employment.

## **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 non-employed among working age mothers of adults with ID and to examine the

effect that care work has on these mothers in terms of, for example, their QOL. We found that non-employed mothers, when compared to their employed counterparts, were older, had received less years of education, had a self-reported lower level of health, had lower social support, had a lower quality of life and had a lower family income; furthermore, their adult children were older and had a lower level of ADL. This suggests that working age mothers of adults with ID who combine both their paid work and care responsibilities are generally younger, better educated, healthier, have a higher level of social support and a better family income; furthermore, their adult children have a higher level of ADL. This partly agrees with the study of Thyen et al. (1999), who found that employed carers had higher level of family support and better health than those who were not employed.

Consistent with previous studies (Baldwin, 1985; Lippe et al., 2003; OECD, 2001), logistic regression revealed that mother age, the adult child's ADL and family income were significantly associated with the mothers' involvement in employment (Table 4). This can explain why some mothers need to give up work because of their child's special care needs and then find it hard to re-enter employment at a later time point. Their difficulties will include, for example, problems finding an appropriate way of combining work and care, particularly when the mother has a lower social status (Baldwin, 1985; Yeandle et al., 2006). Based on our study, it is possible to

suggest that when informal care-giving interferes with the carers' employment, then income and employment-related benefits are affected as well as non-economic costs; this will result in declines in certain aspects of the carer's QOL such as their physical, psychological and environmental wellbeing. Thus, our findings in this area, as presented in Table 1, agree with the findings of Fast et al. (1999). It is necessary to point out that the mother age rather than mother health was strongly associated with mothers' involvement in the labor force even though our participants were all younger than 65. This would suggest that some of non-employed mothers had left their paid work either because they had retired before 65 or because there was not enough support available to the adult with ID's with respect to long-term care-giving (Einam & Cuskelly, 2002; Shearn & Todd, 2000; Todd & Shearn, 1996; Thyen et al., 1999). One concern with this study was the possibility of confounding factors between the carer's age and the carer's health. Although we found that there was a significant correlation between these two variables ( $r=0.189$ ,  $p<0.01$ ), health did not show a significant relationship with the mothers' involvement in employment while the mother age was excluded from the regression analysis model.

Surprisingly, our census survey showed that, after combining full-and part-time employment among these working age mothers, there was not much difference from the general female working population aged 15 and older; this was 53.6% and 49.4%

respectively for Taiwan in 2007 (Directorate-General of Budget, Accounting & Statistics, Executive Yuan, Taiwan, 2008). However, compared with the Taiwanese population in general (Yao et al., 2004) and within the groups, the QOL among the working mothers who combined paid work and care responsibilities was not as good as the general Taiwanese population and the QOL of these mothers was still better than that of non-employed mothers who were carers. This implies that the mothers' involvement in employment might result in positive effects on their lifelong care-giving work compared to their non-employed counterparts. This is similar to the findings of previous disability studies (Heller, Caldwell, & Factor, 2007; Parish et al., 2004; Shearn & Todd, 2000; Thyen et al., 1999; Walker et al., 1989) and is also consistent with the findings of previous women's studies, where it was found a role as a worker seemed to be beneficial to women (Barnett & Hyde, 2001) and to their family (Ross & Huber, 1985). However, the presence of a causal effect between labor force involvement and wellbeing needs to be confirmed by future studies.

The above also implies that the mothers who were not involved in the employment might have given up their paid work involuntarily, perhaps because they were no longer young or because remaining in the labor force was difficult because of their adult child's lower level of functioning. Firstly, our results confirm the arguments put forward by Baldwin (1985) and Yeandle et al. (2006), who indicated

that it might be more difficult for mothers from a lower social status to remain in paid work or re-enter the labor force when they are trying to combine both paid work and care responsibilities. Secondly the findings of the current study also support the hypothesis of Lippe et al. (2003) who suggested that the greater the care needed by the adult child with ID (that is, the lower level of ADL as presented in our regression analyses), the more time will be invested in the care-giving work by the mothers and this inhibits the mothers' involvement in employment.

There were no significant differences between the groups in terms of carer marital status, whether they had a substitute person to take care of adult child with ID and whether they used family support services. This implies that these working age mothers, regardless of employment status, were mostly married and this 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 part-time employed mothers did not differ significantly from either their full-time employed and non-employed counterparts; the exception was the physical health domain of the QOL, where a significant difference was found between part-time employed and non-employed mothers. From Tables 1 and 2, it can be seen that only 49 (16.2%) of 302 working age mothers studied here were part-time employed 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 part-time employed mothers are in terms of whether they have been involved in full-time employment previously or whether they are more similar to the non-employed mothers and have not found it easy to enter the full-time labor force.

Logistic regression was used to identify the predictors of a “low level of QOL” among the participants. As shown in Table 3, the results of model 1 and model 2 are consistent with the results of model 3 and imply that, regardless of whether the mothers employed or non-employed, the mothers’ self evaluation of health was the strongest factor associated with their QOL. This finding is consistent with previous Western and Taiwanese studies that investigated family carers of persons with ID (Chou et al., 2007a; Greenberg et al., 1993; Seltzer & Krauss, 1989). In contrast and inconsistent with previous studies (Chou et al., 2007a; Smith et al., 1993; Wang et al., 2004; Walden et al., 2000), it was found the children’s level of behavioral functioning (ADL and IADL) was not significantly associated with the mothers’ level of QOL in this study. This supports the hypothesis that the mothers’ self reported health is more meaningful than their adult child’s behavioral functioning when predicting their QOL. One possible explanation for this is that this sort of lifelong care-giving work among working age mothers is affected more directly by the mother’s health than by the

child's behavioural functioning. This differs greatly from the situation with mothers of young children with ID (Olsson & Hwang, 2001; Seltzer et al., 1995; Blacher et al., 1997; Feldman et al., 2007; Emerson et al., 2004).

Other than health, the other significant factors associated with the mothers' low level of QOL differed between the two groups. For example, employed mothers who were less well educated and single were more likely to report a low level of QOL. Among the non-employed group, a lower level of family income and a lower level of social support were found to be significantly related to a lower level of QOL. The findings for the employed group were consistent with the findings of Seltzer and Krauss (1989) and Olsson & Hwang (2001) in terms of the effects of limited education and a lack of a partner. This suggests that these employed mothers with a low level of QOL, who have a low level of education and are single, are limited in their employment opportunities and salary compared to employed mothers with a higher level of education. This supports the idea that income may still be a significant predictor of these mothers' QOL, which would agree with the findings for the non-employed group and with an earlier carer QOL study (Chou et al., 2007a). Moreover, it is possible that single mothers who are employed will lack instrumental and emotional support from a partner and this will lower their QOL compared to their married counterparts.

Unlike the employed group, it was found that non-employed mothers with a lower level of family income and lower social support were more likely to have a low level of QOL. However, in this group, the mothers' education level and marital status were not significantly related to their level of QOL. As discussed previously, these non-employed mothers may have left employment involuntarily or found it difficult to enter the labor force. This could be for a number of reasons, such as being older, being less well educated or having a poorer health status compared to the employed mother group. Unemployment may have resulted in a decline in their social networks and family income; this may have then resulted in the lack of social support and lower family income becoming meaningful factors with respect to their wellbeing.

Model 3 shows consistent findings with model 2 with mothers' health status, family income and social support being significant predictors of a low level of QOL for all participants. This implies when improving the QOL of both employed and non-employed mothers, their personal health and family income cannot be ignored. Furthermore, we also need to pay attention to employed single mothers as a group in addition to targeting non-employed mothers in terms of social networks. As discussed above, Table 1 and Table 2 show that there is a significant difference in the scores for the overall QOL and for three domains of the WHOQOL-BREF between employed and non-employed mothers. In contrast to these findings, employment status was not a

significant factor related to these mothers' low level of QOL (Table 3). If the employment status of a mother of an adult child with ID is not related to their QOL, then this can be explained by the fact that if these mothers want to be involved in labor force, they need to fulfill a number of preconditions such as having a higher level of education, not being too old, being healthier, having a higher level of social support and having an adult child with a higher level of ADL. This result is consistent with the findings found in the Western literature (Baldwin, 1985; Lippe et al., 2003; OECD, 2001; Einam & Cuskelly, 2002; Shearn & Todd, 2000; Todd & Shearn, 1996; Thyen et al., 1999).

It is worthy of note that the use by the mothers of the family support services provided by the local government was not significantly related to their low level of QOL. 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 disabled persons using such services is very limited (Department of Statistics, Ministry of Interior, 2007; Chou & Lin, 2004; Chou et al., 2008).

## Implications

The results of current study firstly suggest that the lifelong care-giving mothers who are now employed and who have made paid work and family care compatible

must not be ignored in terms of welfare and employment policies. Secondly, the related policy makers also need to consider how it is possible to promote wellbeing among this group of working age and lifelong care-giving mothers. In terms of improving the wellbeing of these mothers, issues of health, family income and social support need to be promoted. This approach needs to target those mothers who are able to be involved in labor force, particularly those mothers with a low level of family income and those with an adult child with low level of ADL. Thirdly, the health sectors need to consider the issue of ageing among these lifelong mothers. However, notwithstanding the above, these results do not confirm a causal relationship between the mothers' employment status and their level of health, social support, family income and quality of life. Future research needs to determine whether involvement of these mothers in the labor force can be used to promote their wellbeing including their financial condition and their linkage with social networks. We also recommend that the service systems need to consider how to develop strategies that will increase the use of family support services. Among the mothers surveyed in our study, this is one area that would help support these lifelong care-giving mothers and this would be particularly true for single working mothers and non-employed mothers.

## **Limitations**

Some limitations of the present study need to be acknowledged. Firstly, we did not examine work related factors such as the characteristics of the mothers' work, their working hours, the work positions of the participants and their level of perceived work stress, although we did collect the participants' care-giving related variables such as the hours of care-giving per day and their adult child's ADL and IADL. We suggest that a future study is needed to add such family carer employment related data for the employed mothers to the predictive models. Such an approach could use the work-family conflict interface or the working age mothers' wellbeing as dependent variables (Barnett, 2002; Voydanoff, 2002). Secondly, 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 the cause and effect relationships between the mothers' individual variables and their involvement in the labor force. Moreover, our study is unable to represent variations in the participants' experience over time such the different parts of the life cycle that involved the mother and the adult child with ID. 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 (QOL). This suggests that a longitudinal study to answer this question would be desirable in the future. Lastly, while participants were obtained from census survey in a 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 ID, there is still be 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 by the study's voluntary nature.

In spite of the above limitations, as far as we know, this is the first study in Taiwan to explore the relationship between paid work and family care responsibilities among working age mothers who have an adult child with ID that includes an examination of the association between the mother's employment status and the mother's wellbeing. Hopefully, with increasing attention being given to the wellbeing and involvement in labor force of these lifelong care-giving mothers, the results of this study will highlight the importance of addressing the healthcare of this particular group within society, especially the social support needs of these working age mothers, both employed and non-employed. The present study does add to the limited literature that is available on identified associations among these lifelong carers between paid work and family care responsibilities including gender concerns.

## **Conclusion**

In conclusion, the results showed that non-employed mothers of adults with ID

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 ID show a lower level of QOL than the Taiwanese general population. Our findings also suggest that the working age mothers' personal and family characteristics are more strongly associated with their QOL than their adult's level of behavioral functioning and their employment status. In addition, our study also confirms that having a more demanding level of family care work would seem to conflict with the mothers' paid work, but, in addition to this, other factors such as mothers' age and income level are also significant factors that are associated with women's labor force involvement. This suggests that QOL among mothers of an adult child with ID in Taiwan needs to be a concern, particularly the QOL of mothers who are employed but are also single and have a relatively low level of education as well as the QOL of mothers who are non-employed, but also have a low family income and a low level of social support. This study also indicated that health promotion among these groups of working age mothers is very necessary.

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Table 1

## Characteristics of the participants (n=302)

Characteristics	All participants	1. full time employed (n=113) (37.4%)	2. part time employed (n=49) (16.2%)	3. non-employed (n=140) (46.4%)	F (Scheffè)	$\chi^2$
Adult age (mean)	26.1	24.95	24.73	27.51	7.181** (3>1**; 3>2*)	
Adult ADL (mean/%)	90.5	94.96	87.45	87.89	3.993* (1>3*)	12.919*
Profound (<20)	3.3	0.9	2.0	5.7		
Severe (21-60)	7.0	3.5	10.2	8.6		
Moderate (61-90)	11.9	10.6	20.4	10.0		
Mild (91-100)	77.8	85.0	67.3	75.7		
Adult IADL (Mean/%)	12.1	13.09	10.49	11.94	2.225	7.946
Profound (<10)	37.4	34.5	40.8	38.6		
Severe (10-12)	10.3	9.7	16.3	8.6		
Moderate (13-14)	7.3	9.7	10.2	4.3		
Mild (15-24)	45.0	46.0	32.7	48.6		
Carer age (mean)	52.3	50.8	51.4	53.8	8.786***, (3>1***)	
Carer year of education	8.1	8.7	8.4	7.5	3.584*, (1>3*)	
Carer marital status (%)						0.134
With partner	77.8	77.0	79.6	77.9		
Single/widow/divorced	22.2	23.0	20.4	22.1		
Availability of a substitute person to take care of the adult with ID (%)						0.993
Yes	65.6	65.5	71.4	63.6		
No	34.4	34.5	28.6	36.4		

Carer health (EQ-5D)	6.1	5.8	6.1	6.3	5.683**, (3>1**),	
Carer social support	18.3	19.6	18.9	17.1	3.509*, (1>3*)	
Carer QOL	92.4	95.0	94.0	89.8	6.438**, (1>3**),	
Whether there is use of any family support service (%)						0.216
Yes	30.5	31.0	32.7	29.3		
No	69.5	69.0	67.3	70.7		
Family income (%)						20.266**
<NT\$ 20,000	21.2	13.3	20.4	27.9		
NT\$20,001~40,000	44.0	45.1	36.7	45.7		
NT\$40,001~60,000	21.9	23.0	36.7	15.7		
NT\$60,001~80000	6.3	9.7	4.1	4.3		
>NT\$80001	6.6	8.8	2.0	6.4		

\* $p<0.01$ ; \*\* $p<0.001$

Table 2

## Mother's QOL in four domains (n=302)

Variables	Yao <sup>c</sup> 2004 (n = 132,045)	(1) full time employed (n=113) (37.4%)	(2) part time employed (n=49) (16.2%)	(3) non-employed (n=140) (46.4%)	F (Scheffe) between the three groups
	M±SD	M±SD	M±SD	M±SD	
D1 Physical Health	15.05±2.08	14.71±2.15	14.16±1.97	13.53±2.34	10.918***, (1>3***; 2>3**)
D2 Psychological	13.61±2.27	13.04±2.31	12.90±2.01	12.35±2.07	3.512*, (1>3*)
D3 Social Relationships	14.01±2.10	13.80±1.90	13.59±1.81	13.51±1.79	0.259
D3 Social Relationships (Tw) <sup>a</sup>	14.39±2.20	13.90±1.98	13.74±2.04	13.73±1.82	0.753
D4 Environment	13.21±2.09	13.14±1.88	12.90±1.77	12.52±1.89	3.257*, (1>3*)
D4 Environment (Tw) <sup>b</sup>	13.00±2.15	12.93±1.94	12.72±1.77	12.33±1.91	3.438, (1>3*)

<sup>a</sup> D3 (Tw) means an item related to Taiwanese culture, namely face, was added. D3 means the original WHOQOL-BREF version in the domain of social relationships.

<sup>b</sup> D4 (Tw) means an item related to Taiwanese culture, namely food satisfaction, was added. D4 means the original WHOQOL-BREF version in the domain of the environment.

<sup>c</sup>Survey of Taiwanese General Population (n=132,045 ) (Yao et al. 2004).

Table 3

Predictive variables	Model 1 Employed mothers <sup>a</sup> (n=162)		Model 2 Non-employed mothers <sup>b</sup> (n=140)		Model 3 All non-elderly mothers <sup>c</sup> (n=302)	
	Odds Ratio	(95% CI)	Odds Ratio	(95% CI)	Odds Ratio	(95% CI)
Adult ADL	.983	(.954-1.013)	1.007	(.985-1.029)	.995	(.979-1.012)
Adult IADL	1.037	(.969-1.109)	.947	(.875-1.024)	.999	(.953-1.048)
Carer age	1.031	(.950-1.118)	.985	(.909-1.069)	1.006	(.953-1.062)
Carer education	.607*	(.381-.967)	1.277	(.813-2.007)	.904	(.676-1.208)
Carer marital status (single)	3.263*	(1.134-9.393)	.721	(.236-2.199)	1.412	(.695-2.870)
Availability of a substitute person to take care of the adult with ID (No)	1.638	(.658-4.074)	2.020	(.746-5.467)	1.479	(.784-2.788)
Family income	.577	(.341-.977)	.551**	(.355-.854)	.582**	(.426-.795)
Carer health (EQ5D)	3.022***	(1.876-4.870)	3.290***	(1.967-5.503)	3.130***	(2.235-4.383)
Carer social support	.954	(.895-1.017)	.997**	(.937-1.061)	.979**	(.939-1.022)
Whether use family support services (Yes)	.909	(.388-2.129)	.745	(.283-1.964)	.827	(.444-1.541)
Carer employment status (Yes)					.948	(.530-1.696)
N	162		140		302	
Model Chi-square	74.402***		52.203***		116.488***	

Logistic regression analysis in relation to the mothers' low level of QOL

a 10 independent variables

b 10 independent variables

c 11 independent variables; whether carers were employed was included

\*  $p < 0.05$ ; \*\*  $p < 0.01$ ; \*\*\*  $p < 0.001$

Table 4  
 Logistic regression analysis of mothers' involvement in the employment  
 Predictive variables

	Odds Ratio	(95% CI)
Adult ADL	1.016*	( 1.001-1.031)
Adult IADL	.966	(.926-1.007)
Carer age	.929**	(.888-.973)
Carer education	1.029	(.803-1.319)
Carer marital status (single)	1.420	(.764-2.641)
Availability of a substitute person to take care of the adult with ID (No)	.910	(.529-1.565)
Family income	1.296*	(1.004-1.673)
Carer health (EQ5D)	.834	(.668-1.042)
Carer social support	1.016	(.981-1.052)
Whether there was use of family support services (Yes)	.768	(.451-1.310)
N	302	
Model Chi-square	33.623***	

\*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$