

Making Work Fit Care: Reconciliation Strategies Used by Working Mothers of Adults with Intellectual Disabilities

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Background This study explored the experiences of working mothers with an adult child with intellectual disabilities to understand how they reconcile paid work and care responsibilities.

Methods Fifteen working mothers in Taiwan with an adult child with intellectual disabilities were interviewed, and an interpretative phenomenological approach was adopted for data collection and analysis.

Results All included mothers prioritized their caregiving role over paid work. The strategies used by these mothers to make paid work fit with caregiving included having strong social networks and informal support for

their care work, use of formal services, personal religious beliefs and positive attitudes towards care, as well as having flexible working hours due to self-employment, good relations with employers, working positions and work locations.

Conclusions Formal systems, which include both welfare and labour policies, need to be responsive to and involved in supporting these working mothers, especially those who lack good personal networks.

Keywords: caregiving, intellectual disability, mother, paid work, work-care reconciliation

Introduction

Despite the considerable research focused on the intersection of employment and caregiving among in-family carers of children, the reconciliation of paid work and care responsibilities of mothers having adult children with intellectual disabilities has seldom been addressed. The stress and caregiving burdens experienced by informal and unpaid carers of persons with intellectual disabilities have been extensively studied in recent decades (Seltzer & Krauss 1989; Heller *et al.* 1997a,b; Maes *et al.* 2003; Essex & Hong 2005). 'Care' also has unique meanings for mothers with children with intellectual disabilities (Traustadottir 1991); some mothers have even developed coping strategies to negotiate their care responsibilities in a family (Chang 2009). Having a child with disabilities profoundly impacts employment participation among women (Traustadottir 1991; Thyen *et al.* 1999; Shearn & Todd 2000; Kuhlthau & Perrin 2001; Parish *et al.* 2004; Olsson & Hwang 2006); some carers might leave their paid work because they lack adequate support in caring

for their children in the long term (Todd & Shearn 1996; Thyen *et al.* 1999; Shearn & Todd 2000; Einam & Cuskelly 2002; Parish *et al.* 2004; George *et al.* 2008). However, both Western and Taiwanese studies of working mother carers of family members with intellectual disabilities are limited, especially with respect to their strategies to reconcile their paid work and family care responsibilities.

The Social Context of Taiwan

According to Department of Statistics, Ministry of Interior, Taiwan (2011) most individuals with intellectual disabilities (93%) live with their families who take care of them; 57% of primary family carers are the mothers of individuals with intellectual disabilities. Social services, including cash payments, for individuals with disabilities are limited (Fu *et al.* 2000; Chou *et al.* 2008). For instance, subsidies for a family with members with disabilities are available only for low-income families, which the government determines based on a means test. To be eligible, a family must rate either

'poor' or 'near poor'. In addition to family subsidies, available family support services include home care, respite, day care and day services (vocational training, sheltered employment, supportive services); co-payment is required for such services and is based on the level of family income and the severity of the participant's disabilities. However, those individuals receiving family subsidies are ineligible for other social services, including residential services and the above family support services. Under such a social welfare policy of 'less eligibility', previous Taiwanese studies (Chou *et al.* 2008, 2010) have pointed out that families having a family member with intellectual disabilities receive extremely limited support from formal systems.

In Taiwan, governmental policies aimed at reconciling paid work and family caregiving are not firmly institutionalized. Since 2002, the amended Act of Gender Equality for Employment has allowed employees to take up to 7 days per year of unpaid leave to care for family members with disabilities. Later, the amended Employment Insurance Act of 2009 established a government subsidy of 60% of the salary of workers who take parental leave for a maximum of 6 months to care for children under 3, but this was not extended to parents of adult children with disabilities, whose leave remains unpaid. Consequently, reconciliation between paid work and family caregiving is still largely viewed as a family responsibility in which employers are not obligated, despite public awareness of this social issue. Based on the nationwide data in 2010, the overall employment rate was 49% for women and 68% for men between 15 and 65 years old. However, Taiwan's statistics regarding maternal employment for children with intellectual disabilities is lacking.

Work-Family Interface

From a psychological perspective, women's caregiving is motivated by their emotional attachment to the care receivers, as well as by their capacity for self-sacrifice and sense of altruism (e.g. sacrifices herself to be a 'good daughter', 'good mother' and 'good wife'), and that caring is central to their identity (Hooymann & Gonyea 1995; Pascall 1997). Feminists argue that caregiving is a social construction in which women identify caregiving as an essential part of womanhood, as passed down from generation to generation through mothering (Graham 1983; Dalley 1988; Hooymann & Gonyea 1995). Collins (1990) indicated, after listening to women's experiences, that women live in multiple realities of caregiving that are shaped by class, race,

ethnicity, sexual orientation and age cohort experiences. From a social constructionism perspective, two dominant discourses have been put forward: the 'intensive mother' who selflessly expends her time and energy in nurturing her child and the 'successful woman' who individually competes in the public realm in pursuit of challenging yet satisfying career (Hays 1996; Hughes 2002). Kahu & Morgan (2007) additionally argue that women's lives are influenced by the prevailing local culture and policies.

The following 'demand hypothesis' was proposed by Lippe *et al.* (2003): as more time is demanded by the labour 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. From a resource perspective, social support can act as a buffer between workplace responsibilities and the caregiving role to help mitigate these adverse effects (Barnett & Hyde 2001).

Although the interface between work and family has received considerable attention, the reconciliation between caregiving and paid work has seldom been explored for mothers of adult children with intellectual disabilities. Therefore, this qualitative study aims to explore the paid work and caregiving conditions of working mothers in Taiwan with respect to how they reconcile their paid work with caregiving for an adult child with intellectual disabilities. This study is unique in its emphasis on discussion of the issue from the working mothers' own perspectives. Results of this study provide a valuable reference for efforts to identify the unmet needs of lifelong female carers in relation to the state, employers and social networks.

Methods

Participants

For the purposes of this study, the preliminary criteria for study participants invited to interview were initially: (i) mothers younger than 65 years old who worked for 30 hours or longer each week and (ii) the adult family member receiving care had significant intensive care needs. In other words, the individual had severe intellectual disabilities, was aged 18 years or older and lived with family without any residential care service. First, the participants were recruited through a census survey on health and social care issues in a city in Taiwan ($n = 796$; for further detail, see Chou *et al.* 2010). Second, the working mothers were recruited through two parental organizations and 3 day care service centres that were located in other cities and counties

around Taiwan. In the end, 15 working mothers who have an adult child with intellectual disabilities completed our semi-structured interviews at their homes between October 2008 and May 2009.

The mothers ranged from 41 to 56 years old. Eleven were married, two were divorced, one was separated, and one was widowed. Their educational levels ranged from primary school to college. Their adult children with intellectual disabilities ranged from 19 to 33 years old, and 8 of the 15 were female (Table 1 provides further details).

Research design

An attempt was made to explore the perceptions and experiences of the working mothers by designing open-

ended questionnaires to investigate the following areas: paid work and caregiving conditions; the characteristics of current and previous paid work; coping strategies of mothers in reconciling paid work and care responsibilities; support from family, friends, neighbours, colleagues and employers in helping the mother balance paid work and caregiving; and role of formal services in reconciling the difference between the two roles. To control social desirability bias, the authors used both direct and indirect questioning for sensitive issues.

The interviews were held one-on-one with the working mothers, and the interviews' duration ranged from 50 to 120 min. The interviews were undertaken by three researchers of this study in the participant's home. The principle investigator (PI) invited all researchers to have

Table 1 Characteristics of the 15 working mothers and their adult children with intellectual disabilities

<i>Mothers</i>				<i>Adult children with intellectual disabilities</i>			
<i>Age</i>	<i>Marital status</i>	<i>Education</i>	<i>Paid work/employment</i>	<i>Age and sex</i>	<i>Level of diagnosed intellectual disabilities; ADL & IADL</i>	<i>Service use</i>	
#1	45+	Married /separated	Primary	Cleaner at shoe company	26/F	Severe; mild & profound	Day care
#2	45	Married	Senior high	Self-employed family business – electric repair	20/M	Profound; moderate & profound (mental health problems)	None
#3	45+	Divorced	Senior high	Childminder at home	27/F	Profound multiple disabilities; profound/profound (bedridden; polio; epilepsy)	Home care
#4	50+	Married	Primary	Self-employed hairdresser at home	27/F	Profound; severe & profound (has been lost; hyperactive)	Respite
#5	50+	Divorced	Primary	Cleaner at hotel	24/M	Severe; mild & profound (has been lost; violent behaviour)	Day care
#6	45	Married	Junior high	Self-employed tailor at home	20/F	Severe; mild & profound	Day care
#7	55	Married	Junior high	Factory worker	30/M	Severe; mild & profound	Day care
#8	50	Married	Senior high	Nurse	20/M	Severe; mild & profound (autism)	Day care & respite
#9	45+	Married	Senior high	Self-employed family business – bill accounting	20/F	Moderate multiple disabilities; moderate & profound	Day care
#10	45+	Married	Senior high	Governmental official	19/M	Moderate; moderate & profound	Day care
#11	55+	Married	College	Principal of kindergarten	27/M	Profound multiple disabilities (brain injury); moderate & profound	Day care
#12	55+	Widow	Senior high	Self-employed family business – stock counselling	33/F	Moderate; mild & severe (multiple disabilities)	Day care & respite
#13	50	Married	College	Administrator at day care centre for children with special needs	25/M	Profound; mild & profound (epilepsy; mental difficulties)	Day care
#14	50+	Married	Primary	Self-employed hairdresser at home	20/F	Moderate; mild & profound (challenging behaviour; has been lost)	Day care & respite
#15	55+	Married	Senior high	Governmental official	23/F	Moderate; mild & profound (hyperactive)	Day care & respite

regular team meetings before and after interviews with each participant. The interviews were in mandarin or Taiwanese, depending on the participants' spoken language, and were tape recorded and later transcribed. The authors mailed a copy of the typed transcripts and made a phone call to each participant to check for errors or misunderstandings. Except for making some changes to the characteristic data related to the participants and their families, the mothers agreed with the typed transcripts which were mailed to them for confirmation. Informed consent was obtained from each participant before each interview; the research ethics board of National Yang-Ming University in Taiwan approved the study.

This study aimed to explore these mothers' personal experience of a particular phenomenon (e.g. how they reconciled paid work and care responsibility over the years), by adopting an inductive approach to data collection, in which the transcripts were analysed using interpretative phenomenological analysis (Smith *et al.* 2009). Characteristic data of the mothers and their adult children with intellectual disabilities were collected, such as adult children's age, degree of disability as documented by the government, ADL, IADL and service use and mothers' age, education, length of caregiving (number of years), whether they have a full- or part-time job, marital status, family income and number of family members living in the same household.

The transcripts were analysed by the PI who first noted significant words, phrases or paragraphs and then identified similarities/differences across interviews and emerging themes. The reading process was then repeated by another two co-researchers for the same interviews to check the validity of the analysis and the interpretation of participants' accounts. After all three researchers read each interview transcript, a team discussion followed to confirm our agreement and any differences observed in the themes listed. If all three researchers had different ideas of the themes listed, the authors went back to re-read the transcripts before another discussion. This list was then compared across interviews, and predominant themes were extracted. This resulted in a condensed list of themes, which were then grouped into closely related themes under appropriate headings. Examples of the categories developed included 'self-employment', 'good relations with employers', 'support from family members' and 'spiritual support'. Then, the condensed list of themes was coded with relevant headings as presented in the results section such as 'work flexibility' (e.g. 'self-employment', 'good relations with employers') or

'internal or external family and individual strengths' (e.g. 'support from family', 'spiritual support').

Findings

Mothers' paid work – 'I need the money to feed my kids'

Seven of the mothers were self-employed and working at home. Three mothers (#2, #9, #12) owned family businesses and managed these businesses. Compared to the mothers owning family businesses, the other self-employed mothers, who were hairdressers (#4, #14), a tailor (#6) and a childminder (#3), had both lower educational levels and family incomes. These mothers carried out their hairdressing and clothes making businesses at home. The childminder took care of her sister's grandchild at home from Monday to Friday.

Eight mothers were employed outside of the home. Two each were employed as cleaners (#1, #5; at a shoe store and hotel) and public employees (#10, #15); the others were employed at a factory near home (#7), a day care centre as an administrator for children with special needs (#13), a hospital as a nurse (#8) and a kindergarten as a principal (#11). Seven of them had been employed before they were married and gave birth to their children with intellectual disabilities.

Most of the mothers in the study mentioned that they worked mainly to earn family income. Some of the mothers' income went for day care services or school tuition for their children with intellectual disabilities. Some mothers expressed the difficulty of their employment or employment situation, especially those older mothers with a lower educational level (#4, #5). For example, one mother said: 'I need to work, I need to have money for buying food' (#4).

Based on their responses, the authors found that although the mothers had been through difficult times while looking after their adult children with intellectual disabilities, the majority of them had never stopped paid work. Almost all of the mothers replied that they needed to have paid work for financial reasons, even though it might conflict with their care role. Some of the mothers were even the main breadwinners of their families.

Caregiving responsibilities of the mothers – 'I almost went insane'; 'I was exhausted and did not have time to rest'

All mothers in this study expressed difficulty in taking care of their children with intellectual disabilities,

especially when they were young. The mothers had been exhausted, and some had even contemplated suicide (#2, #12, #13). Some mothers mentioned the most difficult time being when the children were young and when they were too busy to recognize how difficult their life experiences were. One self-employed mother stated: *When he (her son with ID) was 11 and 12 years old, he displayed very disturbed behaviors...which lasted for five to six years; I nearly became hysterical and insane, and was even hospitalized (#2).*

One hairdresser mother (#4) found life extremely hectic as she combined her work and caregiving duties; varicose veins in her legs came from long hours of standing during work, and she explained a typical day as follows: *'last night I went to sleep around 3:00 am; ...I could not sleep well, I had to get up every two or three hours, ...I do not have time to rest'. Other mothers were also extremely busy caring for their children with intellectual disabilities:*

I needed to work early (at the family business), and I also had to prepare meals... I had to take her back and forth to acupuncture therapy daily. I was young and disoriented at that time. I did not know what 'tired' meant...except for when she was at the daycare center (#12).

...I occasionally envied people could enjoy their breakfast... Life was filled with so much tension... I even contemplated suicide... The fact that I have survived is a miracle... (#13).

I have taken care of her for 20 years. I rarely venture outside or to have any social connections outside the family members. ...once she venture outside, she runs away and suddenly becomes lost ...I need a break. I am exhausted (#14).

As discussed above, even when these mothers were the main persons bringing in the family income, they were still the main carers for their children with intellectual disabilities. Unlike the mothers of young children or family carers of ageing parents or spouses, caregiving experiences of the mothers having a child with intellectual disabilities extend for longer time periods. In particular, under the social welfare policy of 'less eligibility', these mothers receive very limited support from the formal systems mentioned above.

Choice between employment and caregiving – 'Family is more important'

When asked 'If you had to choose between employment and caring for your adult child with intellectual disabilities, which one would you choose?' the mothers all prioritized their care responsibilities. Both self-employed and employed mothers would relinquish their employment if forced to choose. Typical comments included: 'Family is more important' (#3); 'Caring for children is natural' (#6); 'When looking after him (son with ID), I feel more of a sense of achievement than when working' (#7); and 'A mother cannot be replaced'. (#15).

Even the two mothers who were working full-time in the family businesses and had strong personalities preferred to be a housewife and a full-time mother:

Although I would have chosen to be a working mother earlier on, I have chosen to be a full time mother (#2).

If my economic circumstances were stable, I would focus entirely on being a housewife... my family is still the top priority. ...I live not only for myself, but for those who need me (#9).

All of the mothers in this study replied they would choose to carry on with only their caregiving role if their family economic conditions allowed it. For these mothers, influenced by traditional values, involvement in paid work was secondary and they were still concerned with their role in child caregiving, which was considered to be different from a man's role (Aryee *et al.* 1999). This role might also be different from that of working women in Western Society (Lu *et al.* 2006; Adya 2008), because having paid work for these Taiwanese women was not something they wanted for themselves but was to meet family needs.

Reconciling paid work and care responsibilities

Caregiving for adults with intellectual disabilities normally requires both a long-term commitment and long hours (typically all day long), as well as including both physical and emotional work. Once deciding to seek employment and take care of an adult with intellectual disabilities simultaneously, mothers must develop strategies to make these dual roles compatible. The main strategies found in this study for these mothers to reconcile their paid work and care

responsibilities were work flexibility (e.g. working hours), building/having family (e.g. strong social networks and social support, use of formal social services) and individual strengths (e.g. personal beliefs) as external and internal resources (as shown in Table 2).

Work flexibility

Flexible working hours significantly impacted the ability of the mothers to reconcile their paid work and care responsibilities. The following coping strategies devised to achieve flexible working hours were found:

Self-employment. Seven of the mothers were currently self-employed. One mother worked 12 hours a day as a childminder for her sister's grandchild from Monday to Friday and said 'I take care of both my sister's grandchild and my daughter (with ID) as well. I cannot leave my daughter and work outside of the home' (#3). Three self-employed mothers, one a tailor and two hair dressers, all working from their homes, stated: 'My work does not conflict with caring for my daughter (with ID). I am used to working late in the evening after my childcare responsibilities and family housework are finished. I can work until late of night' (#6); 'When customers have left, I help her (daughter with ID) take a bath' (#4); 'I am a hair dresser working at my home, which is convenient for taking care of my daughter (with ID)' (#14).

Working at home with flexible working hours explains why these mothers could reconcile their paid work with their caregiving roles. Moreover, one of the self-employed mothers stated that she might be fired if she were employed by a company, owing to her dual roles (#2). To combine the two roles, another self-

employed mother mentioned that, to have free and flexible working time, both she and her husband quit their full-time jobs and started their own family business (#12).

Good relations with employers. Nine mothers were employed outside of the home. In Taiwan, although the 2002 Act of Gender Equality for Employment mandates unpaid care leave, in practice, the policy is seldom implemented. Both the employers and employees are generally unaware that the former is legally obligated to offer care leave for family members to the latter. Consequently, it is usually personal relationships between the employee mothers and their employers that determine whether mothers receive support for balancing their paid work and care responsibilities. The mothers in this study employed by a restaurant, hotel, factory, day care centre for children with special needs, hospital and kindergarten mentioned that their employers were aware that they had a child with intellectual disabilities, which was why they gave them flexible working hours whenever necessary. 'I am most grateful to my employer' was a common expression among those mothers (#1, #5, #7, #13).

The flexible work hours that the mothers received were a favour based on the good relationship with their employers. Some of their employers were previous acquaintances, such as relatives, neighbours, members of their church or former customers, before hiring them. For instance, one of the mothers mentioned that she had been hired earlier by one of her relatives who allowed her son (with intellectual disabilities) to accompany her on a chicken farm where she worked (#5). The mother was thus able to negotiate with her employer for more flexible working hours.

Work position and work location. Two mothers (#8, #11) were leaders of their work units (hospital and kindergarten), subsequently giving them more autonomy in terms of a flexible work schedule, such as when applying for personal leave. Both of them confirmed that without their managerial positions, they would have difficulty in continuing their current employment. The mother (#13) who worked in a rehabilitation centre for children with disabilities mentioned that her work place was on the way to her son's (with intellectual disabilities) day care centre, allowing her go to and return from work and the centre along the same route. She wondered whether she would continue her current employment if it were not for her ideal work location and work schedule. She stated:

Table 2 Themes among mothers making paid work and care fit together

Reconciling paid work and care responsibilities
A. Work flexibility
Self-employment
Good relations with employers
Work position and work location
Civil service
B. Family and individual strengths
External: strong social networks and social support
Support from husbands
Support from family members
Support from neighbours/colleagues/service workers
Use of formal services
Internal: positive personal attitudes and spiritual support
Positive attitudes
Spiritual support

I am able to continue my current employment because my work schedule fits in with my son's schedule for receiving care. As he goes to the daycare center, I go to work. When he leaves the daycare center, I also complete my work (#13).

Civil service. Civil servants often feel more secure than those working in the private sector owing to their stable salary and employee benefits such as personal leave and leisure time off, childcare leave and a retirement pension. Two of the mothers in this study (#10, #15) cited this as a major factor in continuing their current employment. For instance, one of the mothers (#15) working as a civil servant in an income tax bureau reported that as long as she fulfilled her responsibilities, she could not be fired. She was able to more easily combine her dual roles than other working mothers were.

Family/community strengths – strong social networks and social support

Support from husbands. Most of the mothers living with their spouses described their husbands as supportive. For instance, a self-employed mother working at home in a family business (#9) mentioned that not only did her husband perform more housework (60%) than she did (40%), but also that her daughter with intellectual disabilities was extremely close to her husband. A mother working at a hospital (#8) mentioned that she depended heavily on her husband to transport her son with intellectual disabilities to his day care centre, because it was more convenient for her husband to do so. She also felt that her husband contributed significantly to meeting their care needs.

Nevertheless, according to Taiwan's social norms, having a child with a disability is generally viewed as a personal family matter, rather than a matter warranting outside assistance. Consequently, some mothers (#12, #13, #15) complained that, although their husbands could share caregiving tasks and were supportive through their employment and caregiving tasks, socially normative attitudes posed barriers for them, making it hard to receive assistance from immediate family or governmental welfare channels. One employed mother (#13) even noted that the entire family, including her husband, thought she should be solely responsible for taking care of her child with intellectual disabilities because she was the mother.

Support from family members. Some mothers had family members contributing to the caregiving tasks when they and their husbands went out to work. For instance, one mother (#1) mentioned that while she worked as a waitress at a restaurant from afternoon to late evening, her husband, son, daughter and daughter-in-law would help take care of her daughter with intellectual disabilities after she returned from the day care centre in the late afternoon. Two mothers who lived with their husbands' families (#11, #13) described receiving support from their parents-in-law and sister-in-law. One of them mentioned: 'Upon returning from work, I do not need to do much housework... I have a good husband, and mother-in-law; even my father-in-law helps care for her (daughter with ID)' (#11). However, the other (#13) mentioned that, despite living in the same household and sharing housework, her mother-in-law and sister-in-law did not care for her son with intellectual disabilities when she was off to work.

Nearly half of the mothers in this study received a high degree of support from immediate family members, including their mothers (#1, #9, #10, #15), sisters (#7, #10, #15) and brothers (#12). One mother (#15) said her mother was extremely protective of her daughter with intellectual disabilities and provided a great amount of emotional support and encouragement while raising her daughter; her sister helped babysit her daughter before she was three years old. Another mother (#13) even mentioned receiving financial assistance from her father.

Support from neighbours/colleagues/service workers. Two mothers said they were fortunate to have a tremendous amount of support from their social networks; otherwise, they would not be able to continue their employment (#10, #15). One of them (#15) said 'I only have to make one phone call in order to access many resources and assistance from many people... in addition to my colleagues, one of my colleagues' brother-in-law is a physician who has taken care of my daughter and has become a good friend of the family. Also...my good friends, ...the service workers in the kindergarten and daycare center also pay close attention to my daughter...'. Another mother (#10) said 'I am fortunate to have so many resources'. She ranked her mother-in-law as providing the most support, followed by her siblings and mother, and, finally, neighbours. She and her mother-in-law lived in an old residential area for military veterans, in which the neighbours had known each other for 30 years or longer. All neighbours knew her son with intellectual disabilities and, if she

and her family were unavailable, they would occasionally take care of her son after he returned from the day care centre. Within this informal support network, she did not need to use respite care service from formal systems.

However, in comparison with some other mothers in this study, these two mothers with strong personal networks had quite similar social backgrounds including a higher educational level and work experience as civil service employees. Other mothers reported not receiving assistance from friends or relatives; they also felt that their neighbours were not appropriate to offer such assistance or even have contact with (#1, #2, #13, #14). As one mother (#13) explained 'We have little contact with our neighbours, who have no idea of how to get along with my son (with ID).'

Using formal services. With her adult child with intellectual disabilities (#2) not using social services, only one self-employed mother had hired a migrant care worker as of the time the interview was conducted. Eleven of the mothers' adult children with intellectual disabilities used day care services; one used respite care (2 h weekly) (#4) and one used home care (three times weekly at 1 h each time) (#3). Some mothers mentioned that without day care services, they would not be able to continue their caregiving roles (#8, #11, #13).

The mother who did not use formal services and the two mothers who used only very limited respite and home care services were all self-employed. They did not want to use or count on governmental support because such resources were limited. They felt that these services should be reserved for families with children with intellectual disabilities who were in more dire financial circumstances.

A self-employed mother working at home as a hairdresser (#4) had used a day care service previously, but stopped doing so because she had very negative experiences contacting service workers. She thus felt that such services were not useful to her. She described her experiences when her daughter with intellectual disabilities was in a special school as follows: 'When I was working for customers, the teachers from the special school would often call me on how to handle my daughter's condition. I had to leave work immediately to resolve the problem... As I rushed on my motorcycle, I almost crashed into a car on the way. ...The teachers were unfriendly; they only gave me extra work...I have never received governmental support...the more you expect, the more you are disappointed'. At the time of the interview, this mother and her daughter used respite care that was provided

by her friend whom she had known for 20 years. Some mothers (#1, #5, #7, #8, #10, #13) also mentioned that the co-payment for using day care services was too expensive.

The self-employed mother (#2) who hired a migrant care worker to help her with housework mentioned that the migrant care worker was extremely helpful with her housework, and she would not have been able to carry out her dual roles if she had not hired her. Nonetheless, she said that the migrant care worker could not perform the caregiving tasks needed by her son with intellectual disabilities. She said 'I work 10 to 12 hours daily, and I am not as young as before. Without a migrant care worker, I might die while trying to function in the dual roles of mother and working professional. However, I do not ask the migrant care worker to take care of my son (with ID), because she is unfamiliar with my son's conditions'.

Individual strengths – internal positive personal attitudes and spiritual support

Positive attitudes. As with previous analyses, all of these lifelong mother carers had experienced difficulties when taking care of their adult child with intellectual disabilities for 2 or 3 decades while simultaneously functioning in the dual roles of employment and family responsibility. Some mothers adjusted their attitudes towards these roles by taking a more positive approach or learning to ask for assistance to share care responsibilities. Furthermore, some mothers adopted a more positive attitude towards caregiving or towards their life experiences. For instance, one of the mothers (#15) appreciated her daughter with intellectual disabilities in cooperating with her so well that she could continue her professional career. Another mother shared: 'Remaining optimistic is essential; regardless of how happy or unhappy you are with life, you must still live it. Many gods help us to get through life. It just takes time' (#14). The findings also found that the strong personalities of some mothers helped to make their two roles compatible. For instance, the two mothers who had created family businesses said 'I will succeed despite extremely difficult periods of my life' (#2) and 'Self confidence is vital...; I am not a weak individual, I am highly responsible' (#9). Other mothers shared the following:

I now easily accepts my fate in life... For me, I need to both care for her (daughter with ID) and earn an income (for the family business). ...I do not feel that taking care of her is burdensome (#12).

I learned a long time ago how to be good to myself. But learning how to ask others for help has been slow process. ...I have not asked him (the husband) to share in the caregiving work until recently (#13).

Spiritual support. Several mothers cited religious beliefs or attributed their predicament to fate as a means of coping or balancing their dual roles (#2, #6, #8, #9, #11, #12, #13). Such religious beliefs became these mothers' internal spiritual support systems. Our findings also indicated that some of these mothers who cited religious beliefs for coping were also the same mothers who linked fate with their caregiving role (e.g. #2, #8, #9). Additionally, these personal beliefs helped the mothers to modify their attitudes towards care responsibilities to be more positive. One of the mothers living with her parents-in-law even felt that serving as a carer for her daughter with intellectual disabilities was not as difficult as being a daughter-in-law of her parents-in-law. For instance, these mothers shared the following:

Without religious beliefs, I might burn out from exhaustion. ...I watch TV series on the Dar-I channel (a Buddhist TV channel), and understand that other people suffer more than I do. ...I have participated in Buddhist worship, ...I also read religious books, ...I have cried a lot in front of the statue of Pu-sa (a Buddhist deity)...I can feel strength and support from such worship. ...now my life is changed. ...I can accept my fate in life... (#2).

...I have no complaints, and Buddha accompanies those who believe in him and makes things perfect (#6).

Buddhism gives me tremendous moral support. ...life is just like a test; if we respond well, then we can pass the test....Without her (daughter with ID), I may be more narrow minded. ...Now I am more relaxed and open minded than before (#9).

In review of our main findings, it was observed that these mothers were not only combining the roles of caregiving and paid work (Barnett & Hyde 2001; Lippe *et al.* 2003), but they were also using deliberate strategies to make their paid work fit in with their caregiving responsibilities. It is also important to note that the findings of this study pinpoint the differences between the employed and self-employed mothers as

well as the different levels of economic and educational background that are related to the strategies the mothers use to fit paid work with their care responsibilities. In addition, some mothers, including both those who used and did not use day care services, indicated that paying for formal services was a big financial burden. For these lifelong mother carers, cognitive appraisal – or maintaining a positive attitude – is an important coping strategy that can help them to view their situations more positively (Folkman & Moskowitz 2000).

Discussion

'Working carers' rather than 'caring workers'

The mother participants in this study were employed for at least 30 hours weekly and had an adult child older than 18 years old with intensive care needs. All of the mothers were thus middle aged and had been a carer for their adult child with intellectual disabilities for at least 18 years. All mothers compared their difficulty in caregiving for their adult child with intellectual disabilities when he or she was younger with that experienced now. Experiences of these mothers are consistent with those of previous studies, which suggest that caregiving to the young adults with intellectual disabilities (aged 18–40) might be less demanding than that for young children with intellectual disabilities (Fitting *et al.* 1986; Barusch & Spaid 1989; Hooyman & Gonyea 1995; Heller *et al.* 1997a,b).

Although some mothers were even the main income earners of their families, still they continued to function as the main carers of their children with intellectual disabilities. Surprisingly, no mothers complained about the inequity of care responsibilities between themselves and the fathers; rather, some even expressed gratitude for their husbands' support. They viewed taking care of their adult children with intellectual disabilities as their responsibility because they were the birth mothers. This attitude corresponds to traditional ideology on gender roles (Pascall 1997). However, it also reflects Kahu & Morgan's (2007) previous arguments that a lack of formal support would maintain traditional roles in women's lives. Our findings therefore suggest that these lifelong caregiving mothers in Taiwan who are employed are 'working carers' rather than 'caring workers', according to Kröger's (2007) definitions of these two concepts.

Cultivating relationships is key for mothers handling dual roles

Under such societal circumstances, formal support is generally limited in terms of meeting the needs of these lifelong mothers, so informal support becomes a vital strategy for these mothers to combine their paid work and caregiving roles. The mothers have had to build good relationships with their internal and external family networks, such as their husbands, in-laws and colleagues, including service workers, employers from formal social systems and their workplaces. In Taiwanese society, such relationships may overlap, and the boundaries between personal relationships, employment and formal service systems are occasionally inseparable. In other words, working family carers in Taiwan, where the formal support system is inadequate, must utilize various relationships, including those in their personal social networks and workplaces, to reconcile the conflict between paid work and care responsibilities.

Social status differentiates coping strategies used by mothers

According to our findings, the self-employed mothers and the mothers at lower economic and educational levels (i.e. lower social status) had less informal support than the employed mothers and the mothers with higher economic and educational background levels. Thus, the latter, with a higher level of social support, both formal and informal, might be able to maintain employment out of their home. Otherwise, they must develop alternative strategies to make their paid work compatible with their care work; self-employment is an example of such a strategy.

The mothers in our study with a higher social status had more access to social support and resources, including developing good relations with formal service systems. Accordingly, social status of the mothers is meaningful in terms of their links with their social networks. For instance, the mothers in our study who had a higher educational level were employed at a managerial level or worked for the government, thus giving them stronger social networks that offer more support than those mothers with a lower educational level and who were self-employed as a hairdresser, a tailor or a childminder or were employed as a cleaner. This observation is similar to the findings of other empirical studies where the social and demographic factors of family carers were associated with their social

support systems, including their awareness and use of social services; these factors were also identified as affecting the quality of life of the family carers (Barusch & Spaid 1989; Seltzer & Krauss 1989; Chou *et al.* 2007, 2008). In addition, consistent with the results of a previous study (Brandon 2007), these employed mothers increased their available time for caregiving using strong social networks that offered caring support as a result of the special needs of their adult children with intellectual disabilities.

Who is able to use social service as a strategy for combining dual roles?

Compared with the self-employed mothers, nearly all employed mothers with adult children with intellectual disabilities used day care services to reduce their caregiving burden. However, while these employed mothers mentioned the importance of formal services, their experience in using the service was not always a positive one. For instance, the day care services may not fit the work schedule of mothers. Additionally, payment for the formal services may create a large financial burden because the subsidy of the co-payment is based on family income and the severity of the children's disability. Consequently, some of the mothers had to learn how to combine their dual roles without the use of formal services, and self-employment was an alternative that allowed their work to fit in with their caregiving.

Cognitive coping strategies

Our findings further demonstrated that several mothers incorporated their own perceptions, religious beliefs or positive attitudes as part of their strategies for balancing their dual roles. The findings closely resemble those of previous studies (Hong & Seltzer 1995; Smith 1996; Heller *et al.* 1997a,b; Blacher *et al.* 2007; Minnes *et al.* 2007; Chou *et al.* 2011), where positive caregiving appraisals affected the unique lifelong care role of these carers and yielded positive consequences with respect to their psychological well-being. Likewise, our study indicates that religious beliefs have an affirmative impact on mothers' attitudes towards their lifelong caregiving roles.

Implications and Conclusions

In conclusion, according to our findings, the mothers of adult children with intellectual disabilities used their own

resources and developed individual, community and family strengths into strategies to combine their paid work with their care responsibilities. Among the various strategies adopted by the working mothers in this study, the most crucial one is probably their informal support and social network. In contrast, formal support lagged behind in importance for mothers who have spent their lives (e.g. over 20 years) juggling the two roles of caregiver and income earner, particularly for those mothers with limited informal support. This issue deserves special attention, because the working mothers of adult children with intellectual disabilities, who are lifelong carers experiencing unique life cycles and life situations, may gradually lose their supportive networks later on, especially when they undertake additional caregiving roles and become compound carers (Perkins 2010; Perkins & Haley 2010). This situation may worsen in Taiwanese society, in which, based on our study, different social relationships and social networks for an individual are often overlapping and interchangeable. Loss of employment may also lead to reduced informal support for caregiving tasks, as well as a reduction in emotional and health benefits, as suggested in a previous study (Parish 2006). Formal systems must begin to help these lifelong mother carers to obtain the resources that will make their dual roles compatible with each other. How to change Taiwan's policies to support these working mothers and help them reconcile employment and family responsibilities warrants serious consideration. For instance, the authors recommend the current 7-day amount of unpaid leave for care of family members not only be increased but also, more importantly, be amended to become paid and must be routinely implemented, particularly for mothers preferring informal support. Furthermore, formal support, in the form of more formal services such as day care, home care and respite care, should be made available and affordable to them. Additionally, support for grandparents, other extended family members (e.g. sisters of the mothers) and neighbours or colleagues with training and transportation for those mothers has to be considered in the future policy making.

Our study also found that some of the mothers who were able to combine their two roles using their own resources would not choose to use the social services due to wanting to leave such formal resources for those mothers who needed them most. First, this suggests that social services delivery and interventions development need to fit with the timetable of mothers' paid work and meet affordability standards. Second, further research needs to explore the reasons (e.g. affordability, access, eligibility, necessity or distrust of formal services) why some mothers would prefer to use their own resources

rather than count on the government. Meanwhile, future studies are warranted to determine whether informal sources of support are also preferred by mothers of adult children with intellectual disabilities in other societies where formal support is not as limited as it is in Taiwan. In addition, research should be undertaken in other cities and counties in Taiwan as well as in other societies to determine whether the strategies the mothers in this study used to combine work and care would be replicated by those of mothers in similar situations but different locales or social contexts.

Limitations

As described above, the working mothers were first recruited through a census survey and 45 of the participants were working full-time and that the adult child had severe or profound intellectual disabilities; and all these 45 working mothers were invited to join our interview. In the end, only 5 accepted and completed our interviews and 40 mothers declined our following in-depth interview. Majority of the mothers who refuse to be interviewed again in this study replied that they were too busy for their full-time paid work. As a result, another 10 working mothers were from parental support organizations and social service agencies through the research team members' connections. First, generally the participation rate of the mothers approached in this study was relatively low; only 15 working mothers accepted the interview. Second, this convenience sampling, used due to difficulties in identifying the research subjects, cannot generate a representative sample of the population of working mothers of adult children with intellectual disabilities in Taiwan. Third, social desirability bias that might influence the validity of this study is another concern of the limitations. Despite the above limitations, this study significantly contributes to efforts to understand working mothers of adult children with intellectual disabilities in Taiwan and to devise coping strategies for this population group to allow them to reconcile paid work with their care responsibilities.

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