

Paper Contributed to

The 3rd Transforming Care Conference: Innovation and Sustainability

Polytechnic of Milan, Italy

26-28 June 2017

Thematic Panel 17:

Family-based caregiving under transforming regimes: Challenges and opportunities
in Asian societies

Paper Title:

Impact of Caring on Hong Kong Family Caregivers of People with Disabilities

Authors:

Phyllis King Shui WONG

Ritter Cho Fung YEUNG

Melody Hiu Ying FUNG

The Chinese University of Hong Kong

Impact of Caring on Hong Kong Family Caregivers of People with Disabilities

Abstract

Background

Family caregivers' care for family members with disabilities can be challenging and caregiving stress is common. The impact of caring on caregivers has become an increasing concern globally, and many studies have been conducted in different countries to address the experiences and stress levels of caregivers. The findings are beneficial for policy planning and service delivery in relation to those caregivers and their care recipients who have disabilities. There is, however, very little research into understanding caregivers' experiences and the caring process in Hong Kong. The current study is the first of its kind in Hong Kong to examine the situations, stress, and well-being of those who care for people with disabilities.

Methodology

A Hong Kong-wide survey based on a convenience sampling was adopted. Formal invitations were sent to parents' associations, self-help groups, disability services organizations, and special schools, inviting the caregivers to complete the self-administered questionnaires. In total, 846 valid questionnaires were received for analysis. Descriptive and inferential statistical analysis was done on the aspects of *demographic characteristics, caregiver stress level, caring process and participants' views on the disability service provision.*

Results

Results showed that participants were mostly female (82.7%) and the mean age of participants was 46.5 years. Participants who had taken care of family members for more than 10 years comprised 53.2% of the study, while 10.7% had been caring for family members for more than 30 years. Those participants who would undertake caregiving tasks for 11 - 15 hours per day comprised 14.2%, while 27% did more than 16 hours per day. The majority of participants (85.4%) reported sometimes or often feeling mentally exhausted. Around half of participants reported that caring responsibilities affected their relationships with other family members and their social life. A significant effect of disability severity level on participants' psychological state was found ($p = .000$). Most participants found the existing disability services were not adequate, for example 72.9% were dissatisfied with residential service provision, 68% with community-based service and 64% with counseling and support services for caregivers.

Discussion

The findings depict the caring situations of Hong Kong caregivers comprehensively. A comparison of the impact of caring on caregivers between Hong Kong and other countries is made. Cultural issues are discussed and implications for policy and service development are also discussed.

Impact of Caring on Hong Kong Family Caregivers of People with Disabilities

INTRODUCTION

The impact of caregiving on caregivers, particularly the negative aspects, has been substantially mentioned in the literature (Savage & Bailey, 2004). Many studies have been conducted around the world to address the impact of caregiving. Results of these studies show caregivers experience less life satisfaction, less positive affect, and increased levels of psychiatric morbidity, and they experience burnout and reduced employability (e.g. Francesca, Ana, Jérôme & Frits, 2011; Schofield et al., 1998; Schultz, O'Brien, Bookwala & Fleissner, 1995). The substantial evidence of the negative impacts on caregivers may contribute to the formulation of promising, focused, and effective caregiver policies—and the provision of related medical, social, and employment services in many countries.

In addition, the aging of societies is becoming a worldwide trend. It is anticipated that there will be escalating numbers of caregivers devoting themselves to the long-term care of their family members. Meanwhile, with the advancement of medical technology, the life span of people with disabilities is gradually extending, implying that the time period required of caregivers to take care of them is also extending. The “double-aging” phenomenon, which is resulting as both

caregivers and the people they care for are entering old age, has brought increasing concerns for the Asian countries (e.g. Liu, 2010). It is one of our utmost and urgent concerns to provide sufficient and appropriate care and support to caregivers in planning for the required services and development of people with disabilities in the near future.

In Hong Kong, however, there is very little research focusing on the situations of caregivers, particularly the caregivers of people with disabilities. This may be one of the reasons why the issue of caregivers' well-being has not been much addressed by the Hong Kong government. Out of the 83,600 people with different types of disabilities in Hong Kong—disabilities that constrain their physical mobility—80% of them (i.e. 68,300 people) are living with their caregivers, according to the *Persons with Disabilities and Chronic Diseases in Hong Kong* report conducted by the Census and Statistics Department of Hong Kong (2014). Unfortunately, a common feeling verbalized by parents of people with disabilities in Hong Kong is “I wish my child [who has a disability] would pass away earlier than me.” This heartbreaking sentiment reveals the worries and burdens of caregivers. It is difficult to imagine the strain, stress, and inadequacy of support experienced by people with disabilities and their caregivers that would cause them to regard the early death of family members with disabilities as a mercy. When viewed from a global perspective, caregivers in other countries are also facing high-stress situations. Raina et al. (2004) summarized a number of studies on caregiver stress conducted from 1970s to 2000s, findings

show that due to the enormous long-term responsibilities caregivers were facing, caregivers suffered from *increasingly depressed, moderate to high level of distress, depressive symptoms,* and *emotional burden* were commonly identified with links to factors such as duration of caregiving, types of disabilities, and support from the community and social circles.

The current study is the first of its kind in Hong Kong to investigate the situations, stress, and well-being of the caregivers of people with disabilities. This paper consists of six parts. Following this introductory Part 1, Part 2 reviews the models and theories in relation to caregiving developed by western countries. Part 3 outlines the methodology of this study. The study's results are reported in Part 4. Part 5 discusses a comparison of local and overseas differences in caregiving situations and patterns, and proposes a sustainable caregiving model that would be optimal to support both people with disabilities and their caregivers. Lastly, Part 6 sets out the overall conclusions concerning the significance and implications of this study.

LITERATURE REVIEW

Overview of Caregivers' Situations in Different Countries

The literature review begins with revealing the worldwide demographic statistics of caregivers. In the United Kingdom, around 6 million adults help and support family, partners, or friends with illnesses or disabilities, while over 1.5 million caregivers work at least 20 hours per week providing care (Social Policy Research Unit, 2004). In comparison to non-caregivers, caregivers have risk multipliers of 1.2-1.4 (for males) and 1.3-1.6 (for females) due to stress levels, depending on their hours of caregiving.

A report prepared by the Organization for Economic Co-operation and Development (Francesca et al., 2011) summarized the situations among different European countries and South Korea in 2011. Comprising a significant proportion of the population, between 17 and 43.9% of the populations reported that they are required to act as informal caregiver. A predominant proportion of the caregiver population is female and aged 50 to 64. In most of the European countries, the caregivers tended to provide limited hours of care, ranging from 0-9 hours per week, which is a relatively lower intensity. The situations in Spain and Korea were exceptional in that more than half of the reported cases required 20+ hours per week, and thus were higher intensity. The study also investigated the relationship between caring intensity and mental wellness status.

Of the 19 countries considered, 18 reported a higher probability for caregivers to have mental health problems when compared to non-caregivers; the risk ratio ranged from 1 to 1.5, with caring intensity shown to be a varying factor (Francesca et al., 2011).

In Taiwan, according to a 2007 study investigating the situations of caregivers, 70% of the caregivers were female. In terms of relationship to the care recipient, the caregivers were most commonly parents, parents-in-law, or marital partners. On average, caregivers were required to spend 13-19 hours per day, depending on the types of disabilities and whether there were others assisting in the care. This adds up to 91-133 hours per week, which is a long and intense caring schedule. The healthcare issues of recipients included stroke, dementia, and other disabilities. Regarding distress symptoms experienced by caregivers, around half of the participants of the survey reported failure to sleep well, and poor mood (Taiwan Association of Family Caregivers, 2007).

Stages of Caregiving

Overseas studies have also investigated the experience of caregivers in the caring process. Nolan, Grant, and Keady (1996) summarized several stages that the caregiver may experience in the caring process. While scholars have divided the stages in different ways, the overall trajectory has been coherent, as a temporal perspective has been adopted. Wilson (1989a) classified eight

stages of the caring process. With emphasis on the critical elements of taking on and relinquishing control, a five-stage model was provided by Willoughby and Keating (1991).

According to Wilson (1989b), the first stage is “noticing” (1), which means the gradual awareness of aberrant or odd behavior by family members. Willoughby and Keating (1991) also agreed that the first stage begins with denial followed by a gradual acknowledgement that something is wrong. Proceeding through the stages of “discounting/ normalizing” (2), “suspecting” (3), and “searching for an explanation” (4), the caregivers move from denial to emerging recognition. Caregivers seek rational explanations for the odd behavioral changes until such explanations became no longer reasonable or possible. Then they move on to the suspecting stage by realizing that something serious is happening. Eventually, they will move on to the phase of “searching for an explanation” by reluctantly seeking an official diagnosis. Willoughby and Keating’s second stage recognized that gradual acknowledgement leads to the caregivers seeking to gain control by finding out as much information as possible (Willoughby & Keating, 1991).

After receiving a confirmed diagnosis, the process now moves on to the middle stages of the caregiving experience. In Stage 5, there is a retrospective reappraisal of the behavior and events to date. Caregivers proceed to Stage 6, in which they are required to make a decision about future

care options. In this stage, they often have insufficient awareness of the decision's heavy implications for the future. Moving on to Stage 7, described as "going through it," the caregivers learn to take care of an increasingly dependent and frail person on a trial-and-error basis. In the last stage, described as "turning it over," the caregivers develop the gradual realization that the caregiver's own physical and mental health is suffering and that other options are required. Though the caregiver's role may be different after the care recipient is admitted to care services, the caregiver usually continues to play an active role in the caring process (Wilson, 1989a).

It is urged by Nolan, Grant and Keady (1996) that caregivers in different stages are facing different kinds of stress and burdens, so interventions and assistance provided to family caregivers will never be effective until they are tailored to match the specific needs in accordance with the caregiving stages. Nolan et al. further stressed the importance of identifying the appropriate signals for the critical times of transition between stages. More accurate and acute support for caregivers should be provided at these critical times.

Impact on Caring

Psychological Health

From the descriptive statistics, it is not hard to see that a commonly shared problem that

caregivers face is the stress and burden of caregiving, with varying degrees and extents. The findings of many years' worth of substantiated scientific studies show this. Schofield et al. (1998) compared caregivers with non-caregivers, and found that caregivers generally have lesser satisfaction in life, less positive affect, and more negative affect. Schultz and colleagues (1995) conducted a review of 41 studies between 1990 and 1995 regarding the effects on caregivers of dementia patients; they found increased levels of psychiatric morbidity, with elevated levels of depression being a consistent finding across the studies. Boyer and colleagues further verified the occurrence of negative psychological reactions (e.g. anxiety) with the caregiving process (Boyer, Drame, Morrone, & Novella, 2006).

Nevertheless, the caring process was not found to be solely negative. Positive aspects of caring were also identified. Schofield et al. (1998) found that 84% of caregivers reported receiving a great deal of satisfaction from caring. A sense of closeness to the care recipient and enhanced self-esteem were also identified, through the caregiver's efforts to maintain the dignity and potential of the care recipient (Ashworth & Baker, 2000).

In view of the results from the various studies conducted in different countries, it is found that distress is an expected outcome of caregivers. Caring responsibilities, the care recipient's

status, and the intensity of caregiving are all reasons leading to the distress and burden, while the level of distress varies by gender, socio-economic status, disability type, caregiving arrangements, and availability of support.

Physical Health

It is clear that the demands of caring also impact the physical well-being of caregivers. Results of an Australian study that investigated the physical well-being of 424 caregivers show that after controlling for demographic characteristics, the physical health score decreased after 2 years and 4 years for females and males respectively, while the physical health score of non-caregivers remained stable (Kenny, King, & Hall, 2014). The score further deteriorated when the caregivers were actively engaged in the workforce. Furthermore, it is worth noting that the caregivers are entering an aging stage in which they will have their own problems in a developmental sense. However, it was found that these aging caregivers may neglect their own needs, seeking medical advice only reluctantly, or forgetting to take their own regular medications as they instead focus on meeting the needs of their care recipients, resulting in poor control of their own conditions (Pressler et al., 2009). It is also common for caregivers to report symptoms such as fatigue and sleeplessness. With heavy activity and high-intensity caregiving, it is not hard to imagine how fatigue results. Sleeplessness forms a vicious cycle between physical and psychological impacts (Pattenden et al., 2007, Pressler et al., 2009, Saunders, 2008, as cited in

Whittingham, 2009).

Social Support

Social support is also a crucial part of caregivers' well-being. According to Colvin, Cullen, and Thomas (2002) (as cited in Chen, 2012), social support refers to an individual gaining or experiencing emotional, mechanical, or informational support from others. Chen (2012) compared a group of caregiving parents to a group of non-caregiving students. It was found that caregivers experienced a stronger association between caregiving stress and quality of life, which was directly affected by social support. Ergh, Rapport, Coleman, & Hanks (2002) stressed that social support is linked with the severity of the care recipient's disabilities. For those caregivers caring for low-function or high-impairment care recipients, less social support was received because the caregiving occupied most of their time. The situation intensified when the care recipients were functionally dependent or cognitively impaired because their need for supervision escalated. On the other hand, high-functioning care recipients required less supervision, so their caregivers had more time and additional opportunities to be included in social contexts or to seek social support (Ergh et al., 2002).

Employment

According to the 2011 OECD report, which looked at the global impact of caregiving on the caregivers, workforce participation was regarded as one of the economic costs related to caring. It was found that caregivers are 50% more likely than non-caregivers to be unemployed. Apart from the lower employment rate, there is also a phenomenon of lower working hours. For caregivers having medium- to high-intensity work, a direct and significant reduction in the number of working hours is observed. It is deduced that provision of caregiving is already demanding and time-consuming, which is incompatible with full-time employment (Francesca et al., 2011). Data from Australia and the United Kingdom showed that caregivers had a higher tendency to choose a temporary job, which includes a shorter term, with less responsibilities and commitment. Though employment has a direct impact on caregiving outcomes, it is hard for caregivers to be committed to a full-time job. Research has shown that when caregivers struggle with the decision to either stop working or reduce their working hours, they tend to choose part-time work. Though the employment of caregivers is affected, the situation has room for improvement. Concurrent research showed that flexible working hours and a part-time job can be an effective way to include caregivers in the job market, with the effect being most significant for caregivers with low-intensity care and caregiving time totaling less than 10 hours per week (Francesca et al., 2011).

Socio-economic Status

Francesca and colleagues (2011) further established the association of caregiving with a higher risk of poverty. Considering the impact of employment on caregiving, the wages of caregivers were adversely affected due to less job commitment or reduced working hours. In more serious cases, caregivers have no income. Also, workers sometimes choose a lower-paid job in the self-selection process to balance the needs of caregiving and working. In terms of human capital, their skills and work value depreciate with prolonged absences from the workforce, which creates a vicious cycle that affects their engagement in the job market. Looking at various compositions of working hours and households, it has been shown that one's socio-economic status hinges on the caregiving process (Francesca et al., 2011).

Overseas Experiences of Policy Development

In view of the above-mentioned impact of caregiving, overseas examples provided valuable responses in dealing with the situations. Australia developed its policies with reference to scenario projections from 2003 to 2013 as well as research from the Australian Bureau of Statistics (Edwards et al., 2008). In financial support, Australia implemented direct payment for caregivers and the allowance policy enabling caregivers to receive financial support due to the demands of their caregiving roles substantially affecting their workforce participation. In addition, care support programmes were also implemented in the community.

In Malaysia, caregivers were identified as the key to successful rehabilitation. According to Asia Pacific Community Mental Health Development Project (APCMHDP) (2011), family support groups have mushroomed in almost all the states of Malaysia, in the community composed mainly of caregivers. This family support is not only a mutual support, it is also educational: courses are available to help the family recover. Malaysia currently focused on improving the service gaps that Psychiatry Services Malaysia integrated various levels of mental health services with other health services so as to promote patients' sustainable recovery. Outreach is extended to provide support to caregivers with mental illnesses due to their caregiving burden. The service improvement reflects that the Malaysian government emphasized the mental health support to caregivers (APCMHDP, 2011).

In the case of the United Kingdom, the government supports caregivers by a various measures in both local and national regions through NGOs. The United Kingdom structurally supports caregivers via a three-fold framework of responsible agencies, including central government, local agencies, and employers. Both tangible and intangible support measures are covered. These provide, respectively, welfare support (monetary terms), services and caregiving support, and workforce negotiations support, through an emphasis on social responsibility (Yeandle, 2014).

A report upon the care provision for families and its socio-economic impact on care providers by the EU also summarizes the policies of EU nations (Glendinning et al., 2009). They employed a two dimensional care system to support carers. First, various types of financial support for caregivers are provided across European countries, with evidence that such measures can directly or indirectly alleviate the adverse socio-economic impact of care. Although these offer financial incentives, the measures vary according to factors such as the underlying principal, eligibility, interactions with formal care services, means-tested requirements, and so forth. Examples include personal budgets, care allowance to care recipients, care allowance to caregivers, paying caregivers in replacement of formal social services; these measures are implemented with cooperation from current financial safety nets as well as welfare systems at either regional or national level. Second, there are many examples of good practice to support caregivers from public sector and voluntary organizations. These services cover a wide range of measures, each with its own potential to help caregivers, such as prevention of mental health problems for caregivers in the Netherlands, the ACTION project in several EU countries as a system in formal care settings, practicing home care skills in Ireland, and responding to the varying needs that may arise for the caregivers in the caregiving process (Glendinning et al., 2009).

Research Gap

During the literature review, it was found that demographic information of long-term caregivers around the world is readily available and presented by different scholars, NGOs, and government bodies. However, in Hong Kong, the sole available resource is the *Persons with Disabilities and Chronic Diseases* report issued periodically by the Census and Statistics Department of the Hong Kong government. However, the report's content mainly focuses on the situations of people with disabilities, and for their caregivers, only the population and relationship data are provided. In contrast with what is available internationally, further information such as demographic statistics of caregivers (e.g. gender, age, occupation, hours of caregiving, available assistance, and family situation) is not available in Hong Kong.

In the overseas literature, data on the impact of caring and the difficulties encountered by caregivers, such as mental health issues, stress, deteriorating physical health, decreased working time, as well as adverse effects on social life and socio-economic status, is studied and well-recorded. In Hong Kong, a study with cross-sectional and convenience sampling was conducted in relation to caregivers of people with mental illness (Wong, 2010). A qualitative study on caregivers' needs was also conducted in 2010 (Hong Kong Federation of Women's Centres, 2010). However, a quantitative study with the aim of depicting the situations of caring process and its impact is not available in a local context.

In addition, though inadequate, some services do exist to provide support to people with disabilities and caregivers in Hong Kong. It is still worth exploring how caregivers view and evaluate such services, so that the needs and requirements of Hong Kong caregivers can be revealed.

Objectives of the Study

In view of the research gap, the specific objectives of this study are the following:

1. To determine the demographic characteristics of caregivers and their care recipients who have disabilities;
2. To examine the impact of caring on caregivers of people with disabilities; and
3. To explore caregivers' views on the provision of disability services.

METHODOLOGY

Recruitment and Participants

This study was initiated by Hong Kong Alliance on Urging for Sufficient Residential Services (the Alliance), which is a self-help group formed by several parent organizations. A quantitative design for a Hong Kong-wide investigation based on a convenience sample was chosen. A self-administered method was employed.

Formal invitations were sent — to different parents' associations, self-help groups for people with disabilities, NGOs and their service units that serve people with disabilities, and special schools — via Hong Kong Council of Social Services (HKCSS), seeking the concerned bodies' help to distribute the questionnaires to caregivers. Participants completed the questionnaires by themselves and returned the completed questionnaires to HKCSS by post. The collection period was June and July of the year of 2013.

In total, 846 valid questionnaires were received for analysis. Of the participants, 667 (82.7%) were female and 140 (17.3%) were male (N = 807). The caregivers ranged in age from 23 to 86 years (N = 731). The age range of the care recipients was 3 to 69 years. More than half (56.0%) of the care recipients had intellectual disabilities, while the second largest group was care

recipients with autism (38.1%). More than half (55.4%) of the care recipients had one disability; 21.7% had two types of disability; and 22.9% had three or four types of disabilities (N = 797).

The demographic characteristics of the participants are reported in more detail in Table 1.

Table 1 Demographic Characteristics of Participants

Variable	Frequency	%
Sex (N = 807)		
Male	140	17.3
Female	667	82.7
Age Group (N = 731)		
< = 30	35	4.8
31-40	214	29.3
41-50	188	25.7
51-60	185	25.3
61-70	82	11.2
> = 71	27	3.7
Types of Disability of Care Recipients		
ADHD	92	11.5
Autism	305	38.1
Down Syndrome	67	8.4
Hearing Disability	37	4.6
Intellectual Disability	388	47.6
Physical Disability	100	12.5
Mental Illness	64	8.0
Speech Disability	203	25.3
Visceral Disability	44	5.5
Visual Disability	34	4.3
No. of Disability of Care Recipients (N = 797)		
One	442	55.4
Two	173	21.7
Three	88	11.1
> Four	94	11.8

Instrumentation

The questionnaire had four sections. The first section measured the participants' stress levels using the Caregiver Stress Scale (see the appendix). The second section measured the caring process. The third section collected the participants' views towards the sufficiency of disability services provided by the government. The last section collected the demographic data of the participants.

Caregiver Stress Scale

The Caregiver Stress Scale (CSS) was developed by this study based on the 14-item Family Caregiver Stress Inventory developed by the Taiwan Association of Family Caregivers (2013) and the Caregiver Strain Index (CSI) (Chan, Chan & Suen, 2013; Robinson, 1983; Thornton & Travis, 2003).

The 16-item CSS uses a four-point Likert scale (0 = *never*, 1 = *seldom*, 2 = *sometimes*, and 3 = *very often*). The CSS is composed of four domains. The first domain *Physical Well-being* has five items that measure the physical demands of the caring process and how these demands affect the participants' physical health. The second domain *Psychological Well-being* has six items that measure the impact of caregiving on the participants' emotional and psychological states. *Social Well-being* is the third domain, containing three items that measure how the caring responsibilities

affect the participants' social life and relationship with family members. The last domain, *Economic Well-being*, has two items that measure how the caring responsibilities impact the participants' employment and financial situations (see the appendix). The CSS showed very good levels of internal reliability ($\alpha = 0.93$).

Caring Process

This section involves seven items, mainly collecting data about the participants' caring responsibilities in relation to the number of caring hours per day, how many years they have taken care of the family members, the number of sleeping hours per day and so on.

Views Towards the Disability Services Provision

This section aims to collect the participants' views towards the adequacy of eight kinds of disability services provided by the government currently. The eight services include centre-based services, home-care services, respite care (serving people with disabilities), and a sole service for caregivers (focused on caregiver training). The items use a five-point Likert scale (*very adequate, adequate, not adequate, very inadequate, and not applicable*).

Demographic Information

The last section collected demographic information. A total of 17 items of information were

sought, including: gender, age, marital status, education level, and employment status of the participants; and age, types and severity of disability, and services received by the family member(s) with disabilities.

Ethical Concerns

An informed consent was provided along with the questionnaire. The participants were informed of the purpose of the study, potential risks and benefits, voluntary participation, and measures for protecting privacy and data confidentiality.

Data Analysis

The IBM SPSS Statistics – Version 20 software programme was used for descriptive and inferential statistical analysis.

RESULTS

Descriptive Findings

Gender, Age, and Relationship

The results showed that the caregivers were mostly female, with women's responses accounting for 82.7% of the total valid feedback. Regarding age, the age group of 31-40 accounted for the largest proportion (29.3%). Both the 41-50 and 51-60 age groups accounted for more than one-fourth of the participants, 25.7% and 25.3% respectively. Nearly 15% of the caregivers were age 61 or above. Regarding the relationship, the caregivers were predominantly parents, accounting for 88.5% of the participants in this study (see Table 2).

Table 2 Gender, Age, and Relationship

Variable	Frequency	%
Sex (N = 807)		
Male	140	17.3
Female	667	82.7
Age Group (N = 731)		
< = 30	35	4.8
31-40	214	29.3
41-50	188	25.7
51-60	185	25.3
61-70	82	11.2
> = 71	27	3.7
Relationship with Care Recipients (N = 810)		
Parent	717	88.5
Parent-in-law	2	0.25
Sibling	41	5.1
Spouse	12	1.5
Children	27	3.3
Grandparent	8	0.95
Others	3	0.4

Employment Status

Regarding work status, the largest group of the sample was non-working, including housewife, retired, or never employed. These categories added up to 61.1% of the total. Only 24.6% were currently working full-time, and 10.6% were working part-time. Only 3.3% were unemployed or looking for a job (see Table 3).

Table 3 Employment Status of Participants (N = 810)

Variable	Frequency	%
Full-time Job	199	24.6
Part-time Job	86	10.6
Unemployed	36	4.4
Retired	60	7.4
Housewife	426	52.6
Student	3	0.4

Types and Severity of Disabilities

More than half (56.0%) of the people with disabilities in the survey had intellectual disabilities or Down syndrome. The other categories were autism, speech disability, or multi-disability. Regarding multi-disability categories, 21.7% reported having two disabilities and around 22% reported having three or four disabilities. Regarding the severity level of the disability, 40% reported mild, 43.7% reported moderate, and 15% reported severe (see Table 4).

Table 4 Types and Severity of Disabilities of Care Recipients

Variable	Frequency	%
Types of Disability of Care Recipients		
ADHD	92	11.5
Autism	305	38.1
Down Syndrome	67	8.4
Hearing Disability	37	4.6
Intellectual Disability	388	47.6
Physical Disability	100	12.5
Mental Illness	64	8.0
Speech Disability	203	25.3
Visceral Disability	44	5.5
Visual Disability	34	4.3
No. of Disability of Care Recipients (N = 797)		
One	442	55.4
Two	173	21.7
Three	88	11.1
> Four	94	11.8
Severity Level of Disability (N = 749)		
Mild	300	40.0
Moderate	327	43.7
Severe	112	15.0
Others	10	1.3

Family Status

Regarding family status, most of the caregivers had one person with disability at home, but nearly 10% had two or more. As for family size, most participants reported a total of three or four family members, with percentages equaling 30.2% and 36.1% respectively (see Table 5). Regarding the financial situations, 44.8% of the two-person families were below the poverty line¹

¹ Hong Kong's first official poverty line was issued in 2012. Source: http://www.povertyrelief.gov.hk/eng/pdf/20130930_article.pdf

of HK\$7,700 monthly income, 40.6% of three-person families were below the poverty line of \$11,500 monthly income. The percentage decreased as the number of family members increased: 32.3%, 20.9% and 21.1% of participants' family were living under the poverty line of four-, five-, and six-person families, with a baseline at \$14,300, \$14,800, and \$15,800 respectively. In sum, more than 30% (32.9%) of the participants' families were living below the poverty line, on average (see Table 6).

Table 5 Family Status of Participants

Variable	Frequency	%
No. of Family Member(s) with Disability (N = 815)		
One	735	90.2
Two	63	7.7
> = Three	17	2.1
Family Size (N = 808)		
2 Persons	67	8.3
3 Persons	244	30.2
4 Persons	292	36.1
5 Persons	134	16.6
> = 6 Persons	71	8.8

Table 6 No. of Families Living Under Poverty Line

Poverty Line	Family Size	Frequency	%
7,700	2 (n=67)	30	44.8
11,500	3 (n=244)	99	40.6
14,300	4 (n=292)	94	32.2
14,800	5 (n=134)	28	20.9
15,800	> = 6 (n=71)	15	21.1

Caring Process

Regarding the caring process, 73.9% of the participants reported that there was someone to share the caring responsibilities. In most cases, this was the participant's spouse (70.2%). More than a quarter of the participants (26.1%), however, were the sole caregivers in the family. It was also found that nearly 80% of the participants were not employing a household maid to help with the caring process (see Table 7).

Table 7 Share of Care Responsibilities

Variable	Frequency	%
Someone Shares Caring Responsibilities (N = 827)		
Yes	602	73.9
No	213	26.1
Spouse Shares Caring Responsibilities (N = 625)		
Yes	439	70.2
No	186	29.8
Has Employed Foreign Domestic Helper (N = 835)		
Yes	179	21.4
No	656	78.6

The results reveal that the caregiver tended to have a long term of caregiving. More than a quarter of the participants (27.0%) reported that more than 16 hours of caregiving was required per day, while 70.1% of the participants reported that they cannot sleep more than 6 hours per night. Extreme cases like sleeping less than 3 hours made up 15.3% of the total population of participants. Though 46.8% of the participants had taken on the caregiving role for 1-10 years,

26.6% and 15.9% of the participants had been taking care of their family members with disability for 11-20 years and 21-30 years respectively. Meanwhile, 10.7% of the participants had taken on the role for more than 30 years. Nearly 60% (57.7%) of the participants reported that they could only provide caregiving for less than 10 more years, and 23.8% of them reported less than 5 more years (see Table 8).

Table 8 Caring Process of Participants

Variable	Frequency	%
No. of Caring Hours Per Day (N = 745)		
< = 5	232	31.1
6 – 10	206	27.7
11 – 15	106	14.2
> = 16	201	27
No. of Sleeping Hours Per Night (N = 828)		
< = 3	127	15.3
4 – 6	454	54.8
7 – 9	235	28.4
> = 10	12	1.5
No. of Years of Taking Caregiving Role (N = 811)		
1 – 10	379	46.8
11 – 20	129	15.9
21 – 30	216	26.6
> = 31	87	10.7

Impact of Caring

In view of the stress level of the caregivers, three quarters of the participants (76.3%) reported that they sometimes or usually felt burdened in their physical condition. In terms of mental health, 84.5% of the participants reported sometimes or often feeling mentally exhausted;

62.8% reported sometimes or often suffering from sleep disturbance; 66.2% reported sometimes and often feeling exhausted and in a down mood, respectively. A large proportion of the participants (84.2%) felt worried that no one could take care of the care recipient if they were to pass away. Many participants (68.0%) also felt worried and anxious about the future (see Table 9).

Table 9 Caregiving Stress Level of Participants

Item	Never (%)	Seldom (%)	Sometimes (%)	Very Often (%)
You have to take care of him/her even when you are not feeling well physically (N = 834)	6.7	9.9	41.0	42.4
You are mentally exhausted (N = 829)	6.4	9.1	45.1	39.4
The demand for your physical strength is heavy (N = 822)	9.9	13.8	43.3	33.0
You find it difficult to move or transfer his/her body (N = 814)	31.4	19.9	24.2	24.5
Your sleep is disturbed or you cannot sleep well (N = 828)	18.1	19.1	37.7	25.1
Your health deteriorates due to taking care of him/her (N = 825)	21.0	21.5	36.3	21.2
You feel exhausted and down (N = 827)	13.7	20.1	46.1	20.1
Taking care of him/her makes you feel mentally pained (N = 825)	20.6	24.7	39.2	15.5
You feel angry when he/she is with you (N = 827)	19.6	25.9	43.6	10.9
You have to pay attention to him/her all the time (N = 821)	4.1	9.1	29.0	57.8
Your social life with relatives and friends is affected (N = 827)	21.1	22.0	33.0	23.9

Your relationship with other family members is affected (N = 824)	30.0	22.2	33.4	14.4
You are worried that no one could take care of him/her after you pass away (N = 830)	6.6	9.2	29.9	54.3
The cost of taking care of him/her is high and has become a financial burden (N = 828)	14.0	21.7	35.7	28.6
Your family income is affected as you cannot participate in the workforce (N = 823)	30.3	15.5	25.0	29.2
You feel worried or anxious about the future (N = 828)	13.6	18.4	37.5	30.5

A one-way ANOVA test was used to examine the differences in the mean scores in feeling exhausted and down, and feeling worried about the future, among the different disability severity groups. There was significant effect of disability severity level on the participants' psychological state [$F(94, 766) = 16.017; p = .000$]. There was also significant effect of disability severity level on the participants' feeling worried about the future [$F(4, 768) = 7.898; p = .000$].

In view of the social life and relational aspects, more than half of the participants (56.9%) reported that they found the caring process affected their social interaction with their friends and relatives frequently. Nearly half of the participants (47.8%) found that the caring responsibilities frequently affected their relationships with other family members (see Table 9 on above).

In financial terms, 64.3% of the participants felt that the caring caused a financial burden.

Half of the participants (54.2%) recognized that their family income was affected because they could not participate in the workforce (see Table 9 on above).

Views on the Provision of Disability Services

Regarding tangible needs, 72.9% of the participants reported inadequate or very inadequate residential services, both temporary and permanent. A quarter of the participants (27.2%, n = 215) were waiting for residential services for their family members, of which 60.9% had been queuing up for more than 5 years. Similar percentages of perceived inadequacy were reported on day respite services (65.4%), training services (65.1%), and community-based support (68.0%). Regarding the services for meeting intangible needs such as psychological support or counseling, 64.0% of participants reported inadequate or very inadequate provision (see Table 10).

Table 10 Participants' Views the Provision of Disability Services

	Very Adequate	Adequate	Not Adequate	Very Inadequate	Not Applicable
Day Respite Service	1.6%	11.5%	36.2%	29.2%	21.5%
Residential Service	0.9%	3.0%	26.0%	46.9%	23.2%
Respite Service	0.9%	3.0%	26.0%	46.9%	23.2%
Day Training Service	2.3%	16.0%	35.5%	29.6%	16.6%
Home-care Service	1.4%	5.4%	30.3%	33.7%	29.2%
Psychological Support & Counseling	1.6%	7.6%	34.6	30.1%	26.1%
Training for Caregivers	1.6%	11.3%	35.3%	30.5%	21.3%
District Support Centre	2.0%	7.9%	34.0%	34.0%	22.0%

DISCUSSION AND CONCLUSION

Comparing the abovementioned situation with that shown in overseas statistics, they share something common in general and there is something when details are investigated. Regarding the demographic statistics, the caregiving intensity is different. The caregiving hours are in wide variation. In countries like the United Kingdom and other northern European countries, the intensity of caregiving is lower. In these countries, caregivers tended to provide 0-9 hours of care per week. South Korea is the highest case shared, with 60% of cases involving 20+ weekly hours. The case in Hong Kong goes to the extreme. Of the Hong Kong participants in this study, 70% were working 42 to 112 hours weekly in their role as caregiver. From this statistic, it can be observed that the caregiving intensity is unreasonable. Overseas, as an informal caregiver, one might just share caring responsibilities with the community, so that the caregiver's care hours are limited. In Hong Kong, it seems that caregivers take on all the responsibilities of care, including minute-by-minute supervision and caring tasks such as feeding and bathing. Family caregivers who use up all their time and energy in long-term caregiving would be definitely unhealthy, both in terms of psychological and physical well-being. Furthermore, it is possible that caregivers will experience burnout or become exhausted, which is also detrimental to the care recipients. Therefore, an important question remains: Are Hong Kong society and the government focusing enough attention on the hardship and needs of caregivers? In the current situation, it appears that

Hong Kong's provision of support is lacking, and far behind that which is offered in other countries. In western countries, society regards the informal caregivers as supplemental to the disability services offered, while in Hong Kong, the concept seems to be reversed, with disability services treated as additional assistance provided to the caregivers, with the caregivers providing the main care. It is important for society to reflect on whether we are giving sufficient care to people with disabilities, and why the responsibility for care rests solely with family members.

Regarding caregiver age and gender, caregivers are mostly women, which is coherent with Hong Kong. This is possibly due to the social division of labour, in which it is usually the men who go out to earn money. The 2011 OECD report that looked at the global impact of caring on caregivers focused on well-developed countries, like Australia and Europe; some of these countries are famous for their welfare system. In these countries, the percentage of caregivers aged 50 to 64 and 65+ are high (Francesca et al., 2011). Because these well-developed countries usually have low birth rates, it is possible that they are also entering an aging-society phase in terms of population distribution. Their policies on dealing with the aging and the support provided should be a valuable reference for Hong Kong society, which is experiencing similar development of population structure.

Regarding the impact of caring, both the literature review and this study's survey have established that the caregiving process imposes negative impacts on physical health, psychological health, employment status, and socio-economic status. Though there is no common grounding in available statistics to make a data-based comparison, it is suspected that the situation in Hong Kong is much more severe than in other well-developed countries. The negative impacts imposed on caregivers would be further intensified when compared to overseas examples. These negative impacts all occur in areas in which society would be able to provide support, such as stress management and tension release, flexible working hours for caregivers, and so on.

Policy Development

In terms of policy development, the first step for the Hong Kong government should update her mindset towards disability services. It seems that she still perceives disability with an individual model and regards disability as a personal tragedy (Oliver, 1990). This traditional thinking regards disability as a personal issue and lack of luck, therefore, it puts the burden of care on family caregivers. However, family caregivers are regarded as a *public role* by some western countries with the social model of disability. Taking care of people with disabilities is no longer solely a family issue, it is a public act to relieve the government's public expenditure and financial burden in disability services, instead. The United Kingdom example showed us that the care caregivers given has been valued at 119 GBP per year (equivalent to 3,000 GBP annually for

each tax payer) and the UK government recognizes caregivers' contribution to the health and social care system (Yeandle, 2014). Therefore, the social contributions of caregivers and the crucial role they play in society should be affirmed. Instead of providing minimal assistance to people with disabilities, the Hong Kong system requires significant changes, to include caregivers in a system of policies that supports caregivers while benefiting care recipients. There should be three layers of change to address the current situation.

The first layer should be the identification phase. There are currently many cases of caregivers providing caregiving by themselves without any assistance from the government. Unless caregivers are receiving comprehensive social security assistance (CSSA) or queuing for social services, society cannot know their situations. We cannot provide support if these caregivers are not identified. Therefore, in a micro sense, a holistic approach should be adopted. The medical and rehabilitation services should not solely take the care recipients into account, instead the caregivers should also be included in the case file of the care recipients. If the caregivers require support or consultation (e.g. counseling and medical consultation), they should have ways and channels to do so. In a macro sense, overseas countries could provide comprehensive data to share the known demographic situations and the details of their caregivers, such as care hours, impacts, and so on (Francesca et al., 2011). Hong Kong should also have such data to give a clear picture of how many caregivers we have, and how to allocate sufficient

resources to this issue. Without knowing the general situation, we cannot understand the individual situations and the needs of the caregivers.

The second layer should be the recognition phase. What this means is not simply to address caregivers and compliment them, but the more important action of recognizing that they are taking on a large part of the responsibility in a caregiving process that should happen at a societal level. In an effort to help, we can provide direct assistance to the care recipients to lessen the burden and stress for the caregivers. Difficulties such as failure to take up employment, demands for respite care services, and low socio-economic status could all be easily identified. In a more generic sense, the aging population is expected. So how can we plan ahead for expanding the provision of residential services? Addressing the double-aging issue in the long term is also an important consideration. By directly addressing the needs of care recipients, we would show understanding and accountability towards caregivers so that their hardship is acknowledged and their role is dignified.

The third layer should be a phase of support. The negative impacts caregivers face due to their work have been identified and soundly proven by evidence and scholars. Beyond helping with the situation, it is also essential to support them as they deal with the negative impacts. For

example, because it is known that the stress is outstanding, the society could allocate resources to provide counseling or support groups through NGOs and self-help agencies. Different impacts would have their own needs and measures. Methods are easy to think of—what’s more important is the question: are we willing to understand and provide adequate support? Being a caregiver in a prolonged journey without support could be torturous in ways we can never imagine.

It urges the policy-makers in Hong Kong to adopt a contemporary policy mindset and develop the concerned policies with a comprehensive framework. Instead of providing minimal support to care recipients, it appeals for a holistic (the caregivers are included), visionary and innovative model for the caregivers service and policy planning.

CONCLUSION

During the week in which the authors were preparing for this conference paper, there was tragic news about an old-aged couple that the husband (caregiver) killed his wife, who had suffered from stroke required long-term and intense care (South China Morning Post, 2017). The husband’s only escape from the stress and long-term burden was to make a tragic and heartbreaking choice. To prevent this kind of tragedy happening again, it is of utmost importance that this at-risk group of caregivers is identified, recognized, and supported. It is already

undoubtedly hard for paid caregivers in residential homes to do their jobs. Can we imagine the hardship experienced by the household caregivers who have no choice in the matter, who have been doing the job for a long time with great sacrifice, and no earnings? Caregivers are not only contributing to society by releasing society from the social burden of taking care of people with disabilities, but they also safekeeping the dignity of their care recipients. Therefore, the policy-makers should take these caregivers into account in the development of disability services planning. It is urgent to act now, before it is too late, as in the above-mentioned tragedy. In our double-aging society, how long can we rely on our aging caregivers? Will the current direction of caregiving services be sound and sustainable once the caregivers grow old and become care recipients themselves? Whether the current disability service system can withstand a gradual (let alone sudden) escalation of the number of care recipients is highly questionable. Therefore, to support the people with disabilities and to make our society sustainable, we must act today with long-range vision.

Appendix

Caregiver Stress Scale

	Never	Seldom	Sometimes	Very Often
1. You have to take care of him/her even when you are not feeling well physically.				
2. You are mentally exhausted.				
3. The demand for your physical strength is heavy.				
4. You find it difficult to move or transfer his/her body.				
5. Your sleep is disturbed or you cannot sleep well.				
6. Your health deteriorates due to taking care of him/her.				
7. You feel exhausted and down.				
8. Taking care of him/her makes you feel mentally pained.				
9. You feel angry when he/she is with you.				
10. You have to pay attention to him/her all the time.				
11. Your social life with relatives and friends is affected.				
12. Your relationship with other family members is affected.				
13. You are worried that no one could take care of him/her after you pass away.				
14. The cost of taking care of him/her is high and has become a financial burden.				
15. Your family income is affected as you cannot participate in the workforce.				
16. You feel worried or anxious about the future.				

REFERENCES

- Asia Pacific Community Mental Health Development Project (APCMHDP). (2011). *Malaysia: sharing the burden – a focus on carers*. Malaysia: APCMHDP
- Ashworth, M., & Baker, A. H. (2000). 'Time and space': carers' views about respite care. *Health & social care in the community*, 8(1), 50-56.
- Boyer, F., Drame, M., Morrone, I., & Novella, J. L. (2006). Factors relating to carer burden for families of persons with muscular dystrophy. *Journal of rehabilitation medicine*, 38(5), 309-315.
- Census and Statistic Department. (2014). *Social data collected via the general household survey – Special topics report no. 62: Persons with Disabilities and Chronic Diseases in Hong Kong*. Hong Kong: Hong Kong SAR Government.
- Chan, W. C. H., Chan, C. L. F. & Suen, M. (2013). Validation of the Chinese Version of the Modified Caregivers Strain Index among Hong Kong Caregivers: An initiative of medical social workers. *Health & Social Work*, 38(4), 214-221.
- Chen, W.T. (2012). Relationships among parenting stress, social support, and quality of life: Comparisons of parents of people with and without disabilities (in Chinese). *Bulletin of Special Education*, 37(3), 1-26.
- Ergh, T. C., Rapport, L. J., Coleman, R. D., & Hanks, R. A. (2002). Predictors of caregiver and family functioning following traumatic brain injury: Social support moderates caregiver distress. *The Journal of head trauma rehabilitation*, 17(2), 155-174.
- Francesca, C., Ana, L. N., Jérôme, M., & Frits, T. (2011). *OECD health policy studies - Help wanted? Providing and paying for long-term care: providing and paying for long-term care* (Vol. 2011). OECD Publishing.
- Glendinning, C., Tjadens, F., Arksey, H., Morée, M., Moran, N., & Nies, H. (2009). *Care provision within families and its socio-economic impact on care providers*. UK: Social Policy Research Unit of the University of York.
- Hong Kong Federation of Women's Centre (2010). *Report on exploratory study of caregivers' needs*. Hong Kong: the author.
- Kenny, P., King, M.T., and Hall, J. (2014). The physical functioning and mental health of informal carers: evidence of care-giving impacts from an Australian population-based cohort. *Health & Social Care in the Community*, 22(6), 646-659.

- Liu, J. L. (2010). *An exploratory study on double aging: caregiver's burden and social support of adults with intellectual disabilities*. Master Thesis. Taiwan: Soochow University
- Nolan, M., Grant, G., & Keady, J. (1996). *Understanding family care: a multidimensional model of caring and coping*. Buckingham: Open University Press.
- Oliver, M. (1990). *The politics of disablement*. London: Macmillan.
- Pressler, S. J., Gradus-Pizlo, I., Chubinski, S. D., Smith, G., Wheeler, S., Wu, J., & Sloan, R. (2009). Family caregiver outcomes in heart failure. *American Journal of Critical Care*, 18(2), 149-159.
- Raina, P., O'Donnell, M., Schweltnus, H., Rosenbaum, P., King, G., Brehaut, J., ... & Walter, S. D. (2004). Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC pediatrics*, 4(1), 1-13.
- Robinson, B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, 38(3), 344-348
- Thornton, M., & Travis, S.S. (2003). Analysis of the reliability of the Modified Caregiver Strain Index. *The Journals of Gerontology*, 58B(2), S127-S132
- Savage, S., & Bailey, S. (2004). The impact of caring on caregivers' mental health: a review of the literature. *Australian Health Review*, 27(1), 103-109.
- Schofield, H., Bloch, S., Herrman, H., Murphy, B., Nankervis, J., & Singh (Eds.) (1998). *Family caregivers: Disability, illness, and ageing*. Australia: Allen & Unwin.
- Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of dementia caregiving: prevalence, correlates, and causes. *The gerontologist*, 35(6), 771-791.
- Social Policy Research Unit. (2004). *Hearts and Minds: The health effects of caring*. UK: University of York
- South China Morning Post. (2017, June). Hong Kong man who 'strangled disabled wife feared no one would take care of her if he fell sick'. Retrieved from <http://www.scmp.com/news/hong-kong/law-crime/article/2097079/man-strangled-disabled-wife-hong-kong-flat-end-her>
- Taiwan Association of Family Caregivers (2007). *Survey report on family caregivers*. Taiwan: the author.

- Taiwan Association of Family Caregivers (2013). *The 14-item family caregivers stress inventory*. Retrieved from <http://www.familycare.org.tw/policy/10643>
- Willoughby, J., & Keating, N. (1991). Being in control: the process of caring for a relative with Alzheimer's disease. *Qualitative Health Research, 1*(1), 27-50.
- Whittingham, K. (2009). The physical and psychological impact of being an unpaid carer for a heart failure patient. *British Journal of Cardiac Nursing, 4*(8), 354-358.
- Wilson, H. S. (1989a). Family caregivers: The experience of Alzheimer's disease. *Applied Nursing Research, 2*(1), 40-45.
- Wilson, H. S. (1989b). Family caregiving for a relative with Alzheimer's dementia: coping with negative choices. *Nursing Research, 38*(2), 94-98.
- Wong, D. F. K. (2010). *Survey on quality of life of and expectations on rehabilitation services by caregivers of people with mental illness*. Hong Kong: City University of Hong Kong.
- Yeandle, S. (2014). *Supporting working carers in England: rationale for and impact of locality and employer-based approaches*. England: University of Leeds.

END