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1. Background

The World Health Organisation (2020) defined palliative care as an approach that improves the quality of life of patients and their families facing challenges associated with life-threatening illness, which is through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care provides integrated holistic care to patient and offers support to help the family cope during the illness process simultaneously. Such vision is shared by healthcare professionals for elderly care in general.

The physical conditions of patients suffering from any kinds of illness, including degenerative illness, will decline progressively. Greater demands are made on family caregivers as the physical condition of the patient worsens (Brazil et al., 2003).

In 2020, the widespread of COVID-19 certainly added another level of complexity for carers given that they were required to isolate with the person they care for in addition to many social support activities and respite options ceasing or being postponed (Carers NSW Australia, 2020). The stress level of caregivers during the pandemic situation in Hong Kong is uncertain.

2. Literature Review

Aging population and advanced illnesses

The World Health Organisation estimated that 524 million people were aged 65 or older, which is 8% of the world’s population in 2010. Triple growth to about 1.5 billion is expected in 2050 (WHO, 2011).

According to the Census and Statistics Department (2022a), Hong Kong population was 7.29 million in 2022. It is projected to grow to 7.35 million in 2069. Hong Kong has relatively low mortality rate and long life expectancy in general. In 2021, life expectation is 83.2 years for males and 87.9 years for females. The average household size is projected to drop from 2.8 to 2.6 persons per household in 2054 (Census and Statistics, HKSAR 2022b). From 2019 to 2069, the expectation of life is expected to increase 6.2 years and 5.8 years for males and females respectively. (Census and Statistics, HKSAR 2020).

In 2020, 34,179 new cancer cases were diagnosed, the number dropped by 2.6% from the previous year and fell for the first time in nearly 20 years. Compared with a decade earlier, newly diagnosed cases rose by an annual rate of 2.6 %. During the same period, population aged 65 and older increased at 4.2% annually, and the whole population grew slowly at an annual rate of 0.6%. As cancer rates increase sharply with age, the overall increasing burden of cancer is largely contributed by an ageing and growing population. Half of cancers occurred in people over the age of 65 (Hospital Authority, 2022).

In Hong Kong, the average domestic household size is 2.8 (Census and Statistics, HKSAR, 2022a). Due to small household size, more carers are required to tend to more than one care recipients simultaneously. The availability of formal and informal caregivers is decreasing due to increasing longevity and changes in living arrangements. The need of informal caregivers is much higher than the population growth (Lyon & Glucksmann, 2008; Norman & Purdam, 2013).

Roles of family caregivers

Most people with incurable illness prefer to be cared for at home (Henriksson et al., 2015). Family caregivers are taking an important role in palliative care and aged care. Any persons who take the responsibility of the personal care are caregivers, who can be spouses, children, parents, relatives or friends who are involved in the care processes (Henriksson & Arestedt, 2013). Informal caregivers who are unpaid and provide regular care or assistance to friend or family member who has a health problem or disability (Hoffman & Zucker, 2016).

The responsibilities of care range from providing companionship and undertaking household tasks, through assisting with personal care, to performing complex physical and medical tasks, as well as emotional support and coordination of care (McConigley et al., 2010; Henriksson & Arestedt, 2013).

The needs of patients can be diverse and vary from symptom relief to information needs and autonomy to make decisions, psychosocial support for coping with their disease or spiritual and existential questions. Needs of carers are often high in relation to their psychological burden and practical support.

Supporting a family member requiring palliative care, with advanced illness or severe dementia syndrome at home is a complex role that involves new tasks and responsibilities for which family carers often feel insufficiently prepared. Caregiver burden increased significantly with the severity of the dementia syndrome (Graessel et al., 2014).

The HM Government (2008) revealed that 71% of family caregivers had poor physical or mental health. Another survey (2022) showed that 30% of carers reported poor mental health as a result of their caring role with increasing trends (Carers UK, 2022).

Lawton et al. (2000) discovered that women who were carers for at least 12 months were more likely to report poor physical and mental health than those who had not provided any care or provided care of a shorter duration during that time. Edwards & colleagues (2020) reported that nearly 20% of unpaid caregivers in U.S. reported fair or poor health, with wide interstate variation, ranging from 11.7% to 34.4%. Another Asian study revealed that informal caregivers had higher level of depression and worse health outcomes than non-givers (Chan et al., 2013).

On the contrary, Rahring et al. (2009) found no negative impact of health of carers on spouses. The effects of the duration of care on the general health of the caregivers are still a debating issue.

In Hong Kong, family burden and caregiving have been shown to significantly impact the mental health of caregivers in Hong Kong (Wong et al., 2004). Apart from the unfulfillment of the tangible support, additional pressure on carers of uncertain information, unstable finances, changing service landscapes, and loss of social support and recreational activities bring these carers in a vulnerable situation.

At-work and Not-at-work situations

Family members usually take up the role of caregiving in daily life (Yiengprugsawan, 2016). They have difficulty balancing the responsibilities amongst the roles between carer and employee and to maintain their physical and psychological wellbeing.

In Henriksson and Arestedt's (2013) study, 21% of the family caregivers perceived themselves to have no social support at all. Women traditionally have been the primary caregivers across generations (Dellasega, 1990). Recent study (Berecki-Gisolf et al., 2008) found the adverse effects of transitioning into the provision of informal care on reduced labour force participation amongst middle-aged women. Employees are more likely to become caregivers between 45 and 64 years old. Many female caregivers reported that their care responsibilities led to substantial reduction in working hours and income (Wakabayashi & Donato, 2005). Frequent absenteeism may be an indicator that an employee is experiencing difficulties with caregiving responsibilities. Failing to retain these experienced workers will represent a significant loss of resources and knowledge. Carers are more likely to stay with an employer if their needs for flexibility are met. Implementing carer-friendly provisions is therefore a crucial investment in employee retention.

Farfan-Portet et al. (2010) demonstrated the importance of formal employment as a factor modifying the relationship between informal caregiving and adverse health outcomes. Employment plays an important role in understanding the relationship between caregiving and mental health; the reason is that most caregivers are employed and that employment may either provide relief in terms of time away from the caregiving role or add to the overall burden of responsibilities (Yiengprugswan, 2016).

Extra burden under COVID-19 pandemic

Caregiver stress is more obvious during the period of global health crisis, such as COVID-19 pandemic. Patients with advanced illness need intensive professional support. A surge of patients to hospitals makes the family hesitant to bring the patient to the hospital for medical consultation to try to lower the risk of being infected because of being one of the high-risk groups. Caregivers of people with chronic medical conditions rely on daily routine, such as attending day hospital or day centre regularly. Changes in routine for caregivers of people with cognitive issues like dementia can be especially stressful.

Many caregivers reported strong senses of isolation, being easily overwhelmed and prone to burn out. They faced huge physical and mental needs but were unable to get help. There are 42% of carers were unable to access psychotherapist services when needed, and 40%–50% of carers failed to obtain formal care services during the period of severe pandemic situation (April to May 2020) all over the world (Zhang, 2020). Caregiving employees often resulted in strong sense of isolation and depressed feeling. They are unlikely to have adequate time and energy to tend to their own health needs.

During the period of worldwide pandemic situation, the challenges of balancing caring roles, employment and schooling in crowded households amongst different family members caused significant stress for many caregivers, which create tense relationship in some of the families (Carer NSW Australia, 2020). Family caregivers with higher preparedness are believed to have higher levels of hope and caregiver rewards and lower level of anxiety (Henriksson & Arestedt, 2013).

A recent study (2020) found that many carers expressed anxiety on contracting COVID-19 and wondered what would happen if they could no longer provide care to their loved one due to becoming very ill or passing away, as well as what may happen if the person they care for were to contract the virus. Stress and confusion on ongoing changes and unclear messaging from official sources were also prominent issues during the pandemic (Choi, et al., 2020).

3. Research gap and research questions

Research gap

Common challenges of working caregivers include trouble balancing work with caregiving, turning down new projects or promotional opportunities because of time concerns, stress, depression, sleeplessness and physical illness (Nobel et al., 2017). The stress level of caregivers supporting relatives with advanced disease at home is uncertain during the pandemic situation in Hong Kong.

Research questions

(1) Do significant differences exist in demographic and caregiving variables and caregiving stress between at-work and not-at-work family caregivers?
(2) Does any relationship exist amongst family caregiver stress, care recipients' illnesses and culture of their workplace support?
(3) Do family caregivers who are at-work experience a different amount and type of caregiving stress compared with caregivers who are not-at-work?

4. Aims and objectives

This study aims to (1) determine the high-risk factors of family caregiver stress in Hong Kong; (2) investigate the relationship amongst the family caregiver stress, care recipients' illness and the employer support; and (3) explore the differences in types of caregiver stress between at-work and not-at-work caregivers.

5. Methodology

Research design

This work is an exploratory descriptive study using convenience sampling. The sample is selected from a group of hospice services, elderly service organisations and various community centres with carer support. Comprehensive questionnaires were sent to the potential caregivers in written format with return envelopes and/or a Google link.

Eligibility criteria

Inclusion criteria of this study were all individuals over the age 18 who is the family member of the care recipient with an unpaid caregiver role. Their care recipients were suffering from advanced illness or physically frail. They should usually live in Hong Kong and be able to read or communicate in Chinese.

Individuals would be excluded if he/she fall into one of the following criteria. They are aged less than 18, cognitive impairment, history of taking anti-depressant or psychotropic drugs within 1 year or unable to read or communicate in Chinese.

Sample size

The sample size was proposed to be 384 including 192 employed and 192 unemployed participants. A total of 204,200 caregivers are living with disabilities and chronic disease patients in Hong Kong (Census and Statistics, HKSAR, 2022c). According to the calculation, the required sample size to achieve a confidence level of 95% and a margin of error of 5% in a population size of 204,200 in a survey study is 384.

Survey instrument

The questionnaire packet used in this study was composed of (1) the demographic data of caregiver, (2) the main care recipient information, (3) the caregiving variables, (4) Kingston Caregiver Stress Scale, (5) caregiving support in workplace and (6) open-ended questions for supplementary information (Appendix 1).

Kingston Caregiver Stress Scale (2019) is primarily a scale that allows a family caregiver to express their level of perceived stress. It can also be used to monitor changes in stress levels over time as the caregiver's situation changes. The scale is designed for lay caregivers of community-living recipients. The scale has 10 responses that can be further divided into 3 categories: 'Caregiving issues', 'Family issues' and 'Financial issues'. It uses a 5-point rating scale, where 1 indicates no stress, and 5 indicates extreme stress (Kilik & Hopkins, 2019). The Chinese version is available from the authors.

The scale has high internal reliability (ᾳ = 0.88). Alpha coefficient was calculated for each of the sub-scales, that is, Care group ᾳ = 0.85 and Family group ᾳ = 0.75. The Financial group consisting of a single question does not allow for such a calculation (Hopkins & Kilik, 2018). Cronbach Alpha coefficient is commonly used for the measurement of internal consistency. Hinton et al. (2004) suggested high reliability was ranged from 0.70-0.90.

Data collection

Letters with information sheet and questionnaires were sent or distributed to relatives of all users of the participating elderly service organisations and community centre, as well as users of carer support centre. A QR code was attached to the information sheet. The participants could return the hard copy of questionnaires and send it back to the principal investigator using the prepared returned envelopes.

Data were collected from February to September 2021. Non-discriminative snowball sampling was used to encourage the participants to provide multiple referrals and forward the Google link of questionnaires by themselves. Each new referral then provided more data for referral and so on until the number of samples is sufficient. Apart from quantitative data, individualised in-depth interview (Appendix 2) to 10 participants with diversified sociodemographic characteristics was conducted. The participants covered different sexes, social class backgrounds, employment statuses and places of care of their care recipients. The duration of interview ranged from 20 minutes to 50 minutes. The average time of interview was 32.5 minutes. It may help collect more in-depth information on the opinions, thoughts, experiences and feelings of caregivers in daily care issues.

Data analysis

Descriptive statistics was used to depict the frequency, percentage, mean score of different stressors and the perceived stressors. The relationship amongst different variables, such as the demographic data, the main care recipient information and the caregiver stress scale, were calculated using Pearson's correlation and analysis of variance (ANOVA). The relationship between employed status and stress level of caregivers was also calculated by ANOVA. Content analysis was conducted to analyse the qualitative data. All interview data were transcribed verbatim in English and Chinese. The researcher identified the meaningful words or phrases to examine the caregiving issues as perceived by the participants.

Ethical consideration

Formal approval from the Research Ethical Committee of Caritas Institute of Higher Education and participating hospice, nursing home, day care services and community centre had been obtained.

All participants received the information letter explaining the purpose of the study. They need to understand that their participation in this study would not affect their services in that elderly or community centre. They can return the questionnaire by sending it back using the returned envelope. All the participants were anonymous and participated the study voluntarily. All information was kept confidential.

6. Results

Characteristics of the participants

The mixed method study was conducted from February 2021 to September 2021. A total 409 eligible participants who were family caregivers of patients with advanced diseases participated in a quantitative design and 10 of them were invited for in-depth interviews in the study. They were recruited from various non-government organisations, including a private hospice, nursing home, elderly home, cancer centre, day care service centre and community carer centre.

Demographic characteristics

Amongst the 409 participants, 289 (70.7%) were female and 120 (29.3%) were male. Most of the participants (308, 75.3%) were aged over 50. In terms of formal education, 40 (9.8%) attended primary school or below, 157 (38.4%) were at secondary level, 44 (10.8%) attended non-degree post-secondary level, 105 (25.7%) were university graduates and 63 (15.4%) even had master degree or above. Two-thirds of the participants (276, 67.5%) were married, 90 (22.0%) were single and 43 (10.5%) were separated, divorced, widow or widower. Half of them (205, 50.1%) were employed, and the other half of them (204, 49.9%) were unemployed.

More than half of care recipients (232, 56.7%) were parents or parents-in-law of the caregivers. Most of them were tending to 1 care recipient (330, 80.7%) and 2 care recipients (66, 16.1%). The rest of them (13, 3.2%) were tending to 3 or more care recipients simultaneously. Most of the participants (390, 95.4%) had no disabilities. Nearly two-thirds (260, 63.6%) had no any long-term illness. Regarding self-evaluation of health condition, 129 (31.5%) reported that they were healthy, and 178 (43.5%) commented that they were of average health. Details of the demographic characteristics of the participants are shown in Table 1 and 2.

Table 3 shows the distribution of the monthly household income. Monthly household income ranged from no income to more than $80,000 per month.

Table 1: Demographic characteristics of the participants - gender, age, education, marital and economic activity status by whether at work

Demographic characteristic		At work		Not at work		Subtotal	
Gender	Male	72	35.1%	48	23.5%	120	29.3%
	Female	133	64.9%	156	76.5%	289	70.7%
	Total	**205**	**100%**	**204**	**100%**	**409**	**100%**
Age	18–30	15	7.3%	3	1.5%	18	4.4%
	31–40	25	12.2%	4	2.0%	29	7.1%
	41–50	38	18.5%	16	7.8%	54	13.2%
	51–60	89	43.4%	44	21.6%	133	32.5%
	61–70	16	7.8%	64	31.4%	80	19.6%
	71 or above	22	10.7%	73	35.8%	95	23.2%
	Total	**205**	**100%**	**204**	**100%**	**409**	**100%**
Education	Primary or below	6	2.9%	34	16.7%	40	9.8%
	Lower secondary	11	5.4%	32	15.7%	43	10.5%
	Upper secondary	47	22.9%	67	32.8%	114	27.9%
	Diploma or associate degree	25	12.2%	19	9.3%	44	10.8%
	Bachelor degree	68	33.2%	37	18.1%	105	25.7%
	Master degree or above	48	23.4%	15	7.4%	63	15.4%
	Total	**205**	**100%**	**204**	**100%**	**409**	**100%**
Marital status	Single	59	28.8%	31	15.2%	90	22.0%
	Married	126	61.5%	150	73.5%	276	67.5%
	Separated	1	0.5%	1	0.5%	2	0.5%
	Divorced	10	4.9%	7	3.4%	17	4.2%
	Widow/widower	9	4.4%	15	7.4%	24	5.9%
	Total	**205**	**100%**	**204**	**100%**	**409**	**100%**
Economic activity status	Employer	18	8.8%	-----	-----	18	4.4%
	Self-employed	37	18.0%	-----	-----	37	9.0%
	Employee	150	73.2%	-----	-----	150	36.7%
	Unemployed	-----	-----	13	6.4%	13	3.2%
	Housekeeper	-----	-----	78	38.2%	78	19.1%
	Retired	-----	-----	111	54.4%	111	27.1%
	Student	-----	-----	2	1.0%	2	0.5%
	Total	**205**	**100%**	**204**	**100%**	**409**	**100%**

Table 2: Demographic characteristics of the participants - relationship with care recipients, number of patients to tend to and caregiver health status by whether at work

Demographic characteristic		At Work		Not at work		Subtotal	
Relationship with main care recipient	Adult children	11	5.4%	15	7.4%	26	6.4%
	Siblings	10	4.9%	18	8.8%	28	6.8%
	Spouse	29	14.1%	77	37.7%	106	25.9%
	Parents & parents-in-law	146	71.2%	86	42.2%	232	56.7%
	Grandparents	8	3.9%	3	1.5%	11	2.7%
	Uncles and aunts	-----	-----	3	1.5%	3	0.7%
	Children	1	0.5%	2	1.0%	3	0.7%
	Total	**205**	**100%**	**204**	**100%**	**409**	**100%**
No. of patients to tend to	1	165	80.5%	165	80.9%	330	80.7%
	2	33	16.1%	33	16.2%	66	16.1%
	3 or more	7	3.4%	6	2.9%	13	3.2%
	Total	**205**	**100%**	**204**	**100%**	**409**	**100%**
Physical disability	No	198	96.6%	192	94.1%	390	95.4%
	Yes	7	3.4%	12	5.9%	19	4.6%
	Total	**205**	**100%**	**204**	**100%**	**409**	**100%**
Long-term illness	No	155	75.6%	105	51.5%	260	63.6%
	Yes	50	24.4%	99	48.5%	149	36.4%
	Total	**205**	**100%**	**204**	**100%**	**409**	**100%**
Self-evaluation of health	Healthy	80	39.0%	49	24.0%	129	31.5 %
	Average	88	42.9%	90	44.1%	178	43.5%
	Some health issues	34	16.6%	60	29.4%	94	23.0%
	Serious health issues	3	1.5%	5	2.5%	8	2.0%
	Total	**205**	**100%**	**204**	**100%**	**409**	**100%**

Table 3: Monthly household income of the participants

Monthly household income	Frequency	Percentage
No income	47	12.3%
$1–$9,999	45	11.8%
$10,000–$19,999	57	14.9%
$20,000–$29,999	50	13.1%
$30,000–$39,999	49	12.8%
$40,000–$49,999	33	8.6%
$50,000–$59,999	27	7.1%
$60,000–$69,999	21	5.5%
$70,000–$79,999	7	1.8%
More than $80,000	46	12.0%
Missing	27	-----
Total	**409**	**100% (excluding missing)**

Characteristics of the working caregivers

This quantitative study involved 205 working caregivers and 204 non-working caregivers. More than half of the male participants (72 out of 120, 60.0%) and nearly half of the female (133 out of 289, 46.0%) were part of the working force in the society. Apart from their care responsibilities, they were also part of the working force of Hong Kong, including part- and full-time jobs. More than half of the participants (127, 62.0%) were working over 40 hours per week on top of their care responsibilities. They tend to their family member during their rest time. The details of the weekly working hours of the working caregivers are shown in Table 4.

Table 4: Weekly working hours of the working caregivers

Weekly working hours	Frequency	Percentage
Less than 10 hours	16	7.8%
10–19 hours	12	5.9%
20–29 hours	18	8.8%
30–39 hours	32	15.6%
40–49 hours	94	45.9%
50 hours or above	33	16.1%
Total	**205**	**100%**

Amongst the 205 working caregivers, 192 of them were employed. One-third (63, 30.7%) of them were professionals. The rest of the occupations were administrators and managers (30, 14.6%), service and sales workers (28, 13.7%), clerical support workers (22, 10.7%), associate professionals (19, 9.3%), elementary occupations (12, 6.2%), craft and related workers (11, 5.4%) and plant and machine operators and assemblers (7, 3.4%). The details of the distribution of occupation of the employed participants are shown in Table 5.

Table 5: Distribution of occupation of the employed participants

Occupation	Frequency	Percentage
Managers and administrators	30	15.6%
Professionals	63	32.8%
Associate professionals	19	9.9%
Clerical support workers	22	11.5%
Service and sales workers	28	14.6%
Craft and related workers	11	5.7%
Plant and machine operators and assemblers	7	3.6%
Elementary occupations	12	6.3%
Total	**192**	**100%**

Characteristics and illnesses of care recipients

The participants were asked to provide the profile of their main care recipients. All main care recipients suffered from advanced illnesses, including degenerative illness (164, 40.6%), advanced cancer (156, 38.6%), end-stage organ failure (69, 17.1%) and other illnesses (15, 3.7%) in this quantitative study. Apart from the major illnesses, 325 out of 409 care recipients (79.5%) had more than one kind of illnesses. Half of them (210, 51.3%) suffered from 3 kinds of illnesses or above.

Amongst the 409 care recipients, 234 (57.2%) were female and 175 (42.8%) were male. Half of them (206, 50.4 %) were over 80 years old, 120 (29.4%) ranged from 61 to 80 years old, 52 (12.7%) ranged from 41 to 60 years old, 23 (5.6%) ranged from 21 to 40 years old and the rest of them (8, 2.0%) were under 21 years old.

Self-care abilities of the care recipients were as follows: totally dependent (144, 35.2%), great difficulty (116, 28.4%), a bit difficulty (125, 30.6%) and independent (24, 5.9%). Most of the care recipients (349, 85.3%) lived with the caregiver or their own home as usual in the recent 6 months. The rest of them moved to caregiver home temporarily for care convenience (18, 4.4%), long-term care facility (27, 6.6%) and admitted to hospital most of the time (15, 3.7%) recently. Details of the basic information of the main care recipients are shown in Table 6.

Table 6: Basic information of the main care recipients

Demographic characteristic		Freq	Percentage	Total
Age	20 or below	8	2.0%	409
	21–30	14	3.4%	
	31–40	9	2.2%	
	41–50	12	2.9%	
	51–60	40	9.8%	
	61–70	49	12.0%	
	71–80	71	17.4%	
	81 or above	206	50.4%	
Gender	Male	175	42.8%	409
	Female	234	57.2%	
Major illness*	Advanced cancer	156	38.6%	409
	End-stage organ failure	69	17.1%	
	Degenerative illness	164	40.6%	
	Others	15	3.7%	
	Missing	5	-----	
Self-care ability of care recipients	Independent	24	5.9%	409
	A bit difficulty	125	30.6%	
	Great difficulty	116	28.4%	
	Totally dependent	144	35.2%	
Number of diseases or illnesses	1	84	20.5%	409
	2	115	28.1%	
	3	112	27.4%	
	4	50	12.2%	
	5	22	5.4%	
	6 or more	26	6.4%	
Accommodation of care recipients in the past 6 months	Hospitalisation	15	3.7%	409
	Long-term care facility	27	6.6%	
	Live with caregiver as usual	203	49.6%	
	Live with caregiver temporarily for care convenience	18	4.4%	
	Live at own home	146	35.7%	

Note: * The percentages refer to the percentages on valid responses.

Time spent in taking care of recipients

The time spent in tending to the care recipients per week ranged from 1 hour to 168 hours per weeks, with a median of 21 hours per week and a mean of 40.60 hours per week. Table 7 shows the frequency and percentage distributions of time spent.

Table 7: Time spent in taking care of care recipients per week

Hours per week	Frequency	Percentage	Cumulative frequency (%)
Less than 10 hours	124	30.3%	124 (30.3%)
11–20 hours	77	18.8%	201 (49.1%)
21–30 hours	50	12.2%	251 (61.4%)
31–40 hours	35	8.6%	286 (69.9%)
41–50 hours	24	5.9%	310 (75.8%)
51–60 hours	9	2.2%	319 (78.0%)
61–70 hours	25	6.1%	344 (84.1%)
71–80 hours	3	0.7%	347 (84.8%)
81–90 hours	9	2.2%	356 (87.0%)
91–100 hours	11	2.7%	367 (89.7%)
101–110 hours	3	0.7%	370 (90.5%)
111–120 hours	8	2.0%	378 (92.4%)
121–130 hours	5	1.2%	383 (93.6%)
131–140 hours	3	0.7%	386 (94.4%)
141–150 hours	3	0.7%	389 (95.1%)
151–160 hours	0	-----	389 (95.1%)
161–168 hours	20	4.9%	409 (100%)
Total	**409**	**100%**	

Amongst the different genders, female caregivers (n = 289, mean = 42.02) spent longer hours in care activities than male caregivers (n = 120, mean = 37.16). Table 8 presents the time spent in taking care of recipients in different genders.

Table 8: Time spent per week (in hours) in taking care of care recipients in different genders

Gender	n	Mean	Standard deviation (SD)
Female	289	42.02	43.29
Male	120	37.16	42.09
Total	**409**	**40.60**	**42.95**

The results revealed that the caregivers of advanced cancer group (n = 156, mean = 47.29) spent longer hours in care than degenerative illness group (n = 164, mean = 38.89), end-stage organ failure group (n = 69, mean = 31.65) and others (n = 15, mean = 24.27). Table 9 presents the time spent in taking care of care recipients by major illness of care recipients.

Table 9: Time spent per week (in hours) in taking care of care recipients by major illness group

Major illness Group	n	Mean	SD
Advanced cancer	156	47.29	48.57
Degenerative illness	164	38.89	37.99
End-stage organ failure	69	31.65	38.30
Others	15	24.27	40.61
Missing	5	-----	-----
Total	**409**	**40.60**	**42.95**

From the whether-at-work perspectives, the caregivers of not-at-work group (n = 204, mean = 54.33) spent much longer hours than those in the at-work group (n = 205, mean = 26.93).

Within the not-at-work group, unemployed (n = 13, mean = 60.00) and housekeeper (n = 78, mean = 61.45) groups were spending more time in taking care of the recipients than the retired (n = 111, mean = 49.46) and students (n = 2, mean = 10).

Within the at-work group, self-employed persons (n = 37, mean = 35.22) were spending more time in taking care of the recipients than the employees (n = 150, mean = 25.17) and employers (n = 18, mean = 24.56). Table 10 presents the time spent in taking care of recipients in different economic activity status groups.

Table 10: Time spent per week (In hours) in taking care of care recipients by economic activity status and whether at work

Economic activity status				Whether at work			
	N	**Mean**	**SD**		**N**	**Mean**	**SD**
Employer	18	24.56	25.95	At work	205	26.93	27.97
Self-employed	37	35.22	38.54				
Employee	150	25.17	24.79				
Unemployed	13	60.00	41.51	Not at work	204	54.33	50.43
Housekeeper	78	61.45	53.54				
Retired	111	49.46	48.98				
Student	2	10.00	0.00				
				Total	**409**	**40.60**	**42.95**

Relationship between time spent and gender, major illness of care recipients and economic activity status

No significant difference was found between gender and time spent in tending to the care recipients, and even female caregivers (mean = 42.02, SD = 43.29) spent longer hours in care than male caregivers (mean = 37.16, SD = 42.09).

A significant difference was observed between major illness of care recipients and economic activity status and the time spent in tending to the care recipients. Table 11 shows the ANOVA results amongst major illness group (F = 3.127, p = 0.026) and economic activity group (F = 9.190, p = 0.00) representatively.

Table 11: One-way ANOVA for time spent in caregiving of the participants by major illness and economic activity status groups

Group	Time spent	Sum of squares	df	Mean square	F	p
Major illness group	**Between groups**	16973.627	3	5657.876	3.127	0.026
	Within groups	723651.046	400	1809.128		
	Total	740624.673	403			
Economic activity status group	**Between groups**	90785.365	6	15130.894	9.190	0.000
	Within groups	661881.070	402	1646.470		
	Total	752666.435	408			

Common daily activities that need assistance

In the past six months, most of the caregivers accompanied their care recipients for medical consultation (335, 81.9%), provided emotional support (267, 65.3%) and assisted in grocery shopping (257, 62.8%). More than half of the caregivers assisted in dining or prepared food for the care recipients (243, 59.4%), performed housework (222, 54.3%) and assisted in mobility (217, 53.1%). The rest of the activities and support included financial support (183, 44.7%), bathing and dressing (160, 39.1%), continence care (130, 31.8%), rehabilitation support (126, 30.8%), assisted in religious activities (71, 17.4%), provided basic nursing care (69, 16.9%) and offered cognitive care (65, 15.9%).

As reflected in the figures in Table 12, family caregivers showed concern about the process of medical consultation and wish to learn more about their major care recipients' prognosis from the medical practitioners. They also found themselves had a role of comforting their loved one and provide both physical care and emotional support to them. Details of the common daily activity performance by different genders and whether at work are shown in Table 12.

Table 12: Common daily activities the caregiver provided assistance to the care recipients by different genders and whether at work

Common daily activities		**Gender**				**Whether at work**				***Total***
		Male		**Female**		**At work**		**Not at work**		
		Freq	**%**	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**	
a.	Accompanying to consultation	91	75.8%	244	84.4%	166	81.0%	169	82.8%	335 (81.9%)
b.	Emotional support	81	67.5%	186	64.4%	143	69.8%	124	60.8%	267 (65.3%)
c.	Shopping	70	58.3%	187	64.7%	129	62.9%	128	62.7%	257 (62.8%)
d.	Assisting in dining or preparing food	64	53.3%	179	61.9%	109	53.2%	134	65.7%	243 (59.4%)
e.	Housework	65	54.2%	157	54.3%	98	47.8%	124	60.8%	222 (54.3%)
f.	Mobility	61	50.8%	156	54.0%	106	51.7%	111	54.4%	217 (53.1%)
g.	Financial support	64	53.3%	119	41.2%	108	52.7%	75	36.8%	183 (44.7%)
h.	Bathing & dressing	46	38.3%	114	39.4%	75	36.6%	85	41.7%	160 (39.1%)
i.	Continence care	36	30.0%	94	32.5%	60	29.3%	70	34.3%	130 (31.8%)

j.	Rehabilitation training	36	30.0%	90	31.1%	66	32.2%	60	29.4%	126 (30.8%)
k.	Religious activities	18	15.0%	53	18.3%	38	18.5%	33	16.2%	71 (17.4%)
l.	Basic nursing care	15	12.5%	54	18.7%	35	17.1%	34	16.7%	69 (16.9%)
m.	Cognitive care	15	12.5%	50	17.3%	31	15.1%	34	16.7%	65 (15.9%)
Overall		**120**	**100%**	**289**	**100%**	**205**	**100%**	**204**	**100%**	**409 (100%)**

Supports from other family members

Sixty-three (15.4%) participants was the only caregiver to the care recipient. Nearly half of the participants (197, 48.2%) had other family members to help in the daily care, and around one-third (149, 36.4%) of them appointed paid workers for the daily care to the care recipients. Table 13 shows the details of the availability of other paid and unpaid caregivers in this study.

Table 13: Other caregivers apart from the participant

Types of caregivers	Relationship with the participants	Freq	Percentage to all participants
Other family members or relatives	• Siblings	79	19.3%
	• Spouse	32	7.8%
	• Parents	32	7.8%
	• Adult children	26	6.4%
	• Friends	7	1.7%
	• Grandparents	2	0.5%
	• Uncles and aunts	1	0.2%
	• Not specified	18	4.4%
	Subtotal	197	48.2%
Other paid caregiver	• Full-time maid	141	34.4%
	• Part-time helper	8	2.0%
	Subtotal	149	36.4%

Use of community resources

Nearly half of the participants (194, 47.4%) had experience in using community services. The common community services used included day care centre (48, 11.7%), home helper services (27, 6.6%), community nursing services (19, 4.6%), palliative care home services (12, 2.9%), medical social services (5, 1.2%), meals on wheels (4, 1.0%) and non-emergency ambulance services (3, 0.7%). A total of 76 participants (18.6%) indicated that they had used the community service but did not specify the types of community services used. Details on the experience in using community services are shown in Table 14.

Table 14: Experience in using community services

Use of community services		Frequency	Percentage	Subtotal	Total
No		215	52.6%	215 (52.6%)	409 (100%)
Yes	Not specified	76	18.6%	194 (47.4%)	
	Day care centre	48	11.7%		
	Home helper services	27	6.6%		
	Community nursing services	19	4.6%		
	Palliative care home services	12	2.9%		
	Medical social worker	5	1.2%		
	Meals on wheels	4	1.0%		
	Nonemergency ambulance services	3	0.7%		

A total of 170 out of 194 participants (87.6%) were satisfied with the services of good experiences, and the rest of them (24 out of 194, 12.4%) expressed dissatisfaction. Not all the participants had mentioned the types of community services used. Details on the satisfactory level of using community services are shown in Table 15.

Table 15: Satisfactory level of using community services

Types of community services	Very satisfied		Satisfied		Unsatisfied		Very unsatisfied		Subtotal	
	Freq	**%**	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**
Not specified	9	4.6%	47	24.2%	15	7.7%	5	2.6%	76	39.1%
Day care centre	11	5.7%	36	18.6%	1	0.5%	0	-----	48	24.7%
Home helper services	8	4.1%	18	9.3%	0	-----	1	0.5%	27	13.9%
Community nursing services	10	5.2%	8	4.1%	1	0.5%	0	-----	19	9.8%
Palliative home services	6	3.1%	5	2.6%	1	0.5%	0	-----	12	6.2%
Medical social worker	1	0.5%	4	2.1%	0	-----	0	-----	5	2.6%
Meals on wheels	1	0.5%	3	1.5%	0	-----	0	-----	4	2.1%
Nonemergency ambulance services	0	-----	3	1.5%	0	-----	0	-----	3	1.5%
Subtotal	**46**	**23.7%**	**124**	**63.9%**	**18**	**9.3%**	**6**	**3.1%**	**-----**	**-----**
Total	**170 (87.6%)**				**24 (12.4%)**				**194**	**100%**

Stress level of caregiver

The severity of the stressful items was determined by calculating the mean values of each stressful item. The most stressful item was 'Concerns regarding the future care needs of spouse/relative' (mean = 3.07, SD = 1.19). The remaining stressful experiences were 'Feelings of being confined by responsibilities or demands' (mean = 3.02, SD = 1.15), 'Lack of confidence in care ability' (mean = 2.88, SD = 1.12), 'Feelings of being overwhelmed, overworked or overburdened' (mean = 2.80, SD = 1.04), 'Conflicts with previous daily commitments' (mean = 2.69, SD = 1.08), 'Changes in social life' (mean = 2.67, SD = 1.08), 'Conflicts within family over care decisions' (mean = 2.22, SD = 1.11), 'Change in relationship with spouse/relative' (mean = 2.20, SD = 0.99), 'Financial difficulties associated with caregiving' (mean = 2.20, SD = 1.12) and 'Conflicts with family over the support you are receiving' (mean = 2.11, SD = 1.04). Table 16-18 show the mean and standard deviation of perceived stress level by the participants in different aspects, such as gender, major illness of care recipients and whether at work.

Table 16: Mean and standard deviation of Kingston Caregiver Stress Scale by gender

Kingston Caregiver Stress Scale		Gender				Total		Rank
		Male		Female				
		Mean	SD	Mean	SD	Mean	SD	
a.	Concerns regarding the future care needs of spouse/relative	2.94	1.18	3.12	1.18	3.07	1.19	1
b.	Feelings of being confined by responsibilities or demands	1.83	1.09	3.11	1.16	3.02	1.15	2
c.	Lack of confidence in care ability	2.85	1.14	2.89	1.12	2.88	1.12	3
d.	Feelings of being overwhelmed, overworked or overburdened	2.66	0.98	2.86	1.06	2.80	1.04	4
e.	Conflicts with previous daily commitments	2.58	0.99	2.74	1.12	2.69	1.08	5
f.	Changes in social life	2.63	0.97	2.68	1.13	2.67	1.08	6
g.	Conflicts within family over care decisions	2.15	1.06	2.25	1.12	2.22	1.11	7
h.	Change in relationship with spouse/relative	2.21	1.04	2.19	0.97	2.20	0.99	8
i.	Financial difficulties associated with caregiving	2.23	1.00	2.19	0.97	2.20	1.12	8
j.	Conflicts with family over the support you are receiving	2.03	0.96	2.15	1.07	2.11	1.04	10
Total		**25.09**	**7.46**	**26.17**	**7.76**	**25.85**	**7.68**	

Table 17: Mean and standard deviation of Kingston Caregiver Stress Scale by major illness group

Kingston Caregiver Stress Scale		Major illness						Total	
		Advanced cancer		End-stage organ failure		Degenerative illness			
		Mean	SD	Mean	SD	Mean	SD	Mean	SD
a.	Concerns regarding the future care needs of spouse/relative	3.24	1.20	2.91	1.18	2.98	1.17	3.07	1.19
b.	Feelings of being confined by responsibilities or demands	3.06	1.07	2.80	1.32	3.06	1.14	3.02	1.15
c.	Lack of confidence in care ability	2.93	1.08	3.13	1.29	2.73	1.09	2.88	1.12
d.	Feelings of being overwhelmed, overworked or overburdened	2.76	1.06	2.61	1.00	2.91	1.05	2.80	1.04
e.	Conflicts with previous daily commitments	2.74	1.11	2.58	1.03	2.72	1.07	2.69	1.08
f.	Changes in social life	2.69	1.06	2.43	1.02	2.74	1.12	2.67	1.08
g.	Conflicts within family over care decisions	2.10	0.99	2.01	0.94	2.37	1.21	2.22	1.11
h.	Change in relationship with spouse/relative	2.04	0.89	2.07	0.86	2.37	1.08	2.20	0.99
i.	Financial difficulties associated with caregiving	2.09	1.02	2.20	1.07	2.29	1.20	2.20	1.12
j.	Conflicts with family over the support you are receiving	1.90	0.85	2.10	0.95	2.25	1.17	2.11	1.04
Total		**25.54**	**6.84**	**24.86**	**7.75**	**26.43**	**8.32**	**25.85**	**7.68**

Table 18: Mean and standard deviation of Kingston Caregiver Stress Scale by whether at work

Kingston Caregiver Stress Scale		Whether at work				Total	
		At work		Not at work			
		Mean	SD	Mean	SD	Mean	SD
a.	Concerns regarding the future care needs of spouse/relative	3.08	1.14	3.05	1.23	3.07	1.19
b.	Feelings of being confined by responsibilities or demands	3.05	1.05	3.00	1.25	3.02	1.15
c.	Lack of confidence in care ability	2.86	1.11	2.90	1.14	2.88	1.12
d.	Feelings of being overwhelmed, overworked or overburdened	2.76	1.01	2.85	1.07	2.80	1.04
e.	Conflicts with previous daily commitments	2.70	0.95	2.68	1.21	2.69	1.08
f.	Changes in social life	2.60	1.00	2.74	1.16	2.67	1.08
g.	Conflicts within family over care decisions	2.28	1.10	2.16	1.11	2.22	1.11
h.	Change in relationship with spouse/relative	2.26	0.96	2.14	1.01	2.20	0.99
i.	Financial difficulties associated with caregiving	2.26	1.04	2.13	1.18	2.20	1.12
j.	Conflicts with family over the support you are receiving	2.15	1.02	2.08	1.06	2.11	1.04
Total		**25.98**	**7.49**	**25.72**	**7.88**	**25.85**	**7.68**

The results revealed the stress level amongst the caregivers of different genders: male participants (n = 120, mean = 25.09, SD = 7.46) and female group (n = 289, mean = 26.17, SD = 7.76). Table 19 shows the stress level of participants in taking care of recipients in different genders.

Table 19: Perceived stress level of participants in different genders

Gender	N	Mean	SD
Female	289	26.17	7.76
Male	120	25.09	7.46
Total	**409**	**25.85**	**7.68**

The results revealed the stress level amongst the caregivers of advanced cancer, end-stage organ failure and degenerative illness groups. Surprisingly, other major illness group (n = 15, mean = 27.67, SD = 8.89) perceived the highest stress level compared with the three other major illness groups. Within the three major disease groups, higher stress level was found in degenerative illness group (n = 164, mean = 26.43, SD = 8.32), followed by that in advanced cancer group (n = 156, mean = 25.54) and end-stage organ failure group (n = 69, mean = 24.86, SD = 7.75). Table 20 presents the stress level of participants in taking care of recipients in different disease groups.

Table 20: Perceived stress level of participants in different major illness groups of care recipients

Major illness group	N	Mean	SD
Others	15	27.67	8.89
Degenerative illness	164	26.43	8.32
Advanced cancer	156	25.54	6.84
End-stage organ failure	69	24.86	7.75
Missing	5	-----	-----
Total	**409**	**25.85**	**7.68**

From whether at-work perspectives, the stress levels of at-work group (n = 205, mean = 25.98, SD = 7.49) and not-at-work group (n = 204, mean = 25.72, SD = 7.88) were similar.

Within the economic activity status group, self-employed persons (n = 37, mean = 27.39, SD = 7.79) had higher stress level than the employees (n = 150, mean = 25.90, SD = 7.56) and employers (n = 18, mean = 23.83, SD = 5.84).

Within the not-at-work group, housekeepers (n = 78, mean = 27.10, SD = 7.89) had higher stress level than the retired (n = 111, mean = 25.05, SD = 7.95), unemployed (n = 13, mean = 24.77, SD = 6.18) and students (n = 2, mean = 16, SD = 1.41). Details of the perceived stress level of participants in different economic activity statuses are shown in Table 21.

Table 21: Perceived stress level of participants in different economic activity statuses

Economic activity status				Whether at work			
	n	Mean	SD		n	Mean	SD
Self-employed	37	27.39	7.79	At work	205	25.98	7.49
Employee	150	25.90	7.56				
Employer	18	23.83	5.84				
Housekeeper	78	27.10	7.89	Not at work	204	25.72	7.88
Retired	111	25.05	7.95				
Unemployed	13	24.77	6.18				
Student	2	16.00	1.41				
				Total	409	25.85	7.68

Relationship between stress level and gender, disease group and employment status

No significant difference was found between genders in overall stress level of care recipients. Stress level of female caregivers (mean = 26.17, SD = 7.76) was slightly higher than that of male caregivers (mean = 25.09, SD = 7.46). One of the items 'Change in social life' (F = 4.122, p = 0.043) had a significant difference in stress level between different genders.

Some items were significantly different amongst major illness groups in the stress level of participants. These items were 'Change in relationship with spouse or relatives' (F = 4.530, p = 0.004), 'Conflicts with family over care decisions' (F = 5.011, p = 0.002) and 'Conflicts with family over the support you are receiving' (F = 6.387, p = 0.000). The rest of the items had no significant difference.

From the perspectives of economic activity status, 'Feelings of being overwhelmed, overworked or overburdened' (F=2.219, p = 0.040) and 'Conflict with previous daily commitments' (F = 2.365, p = 0.029) were significant. The remaining items had no significant difference. Table 22 shows the ANOVA results between major illness group and economic activity status group for selected stress items of participants.

Table 22: One-way ANOVA between major illness group and economic activity status of selected stress items of participants

Group	Stress item		Sum of Sq	df	Mean Sq	F	p
Major illness group	Change in relationship with spouse or relatives	Between Groups	12.971	3	4.324	4.530	0.004
		Within Groups	381.789	400	0.954		
		Total	394.760	403			
	Conflicts with family over care decisions	Between Groups	17.910	3	5.970	5.011	0.002
		Within Groups	476.592	400	1.191		
		Total	494.502	403			
	Conflicts with family over the support you are receiving	Between Groups	20.001	3	6.667	6.387	0.000
		Within Groups	417.531	400	1.044		
		Total	437.532	403			
Economic activity status	Feelings of being overwhelmed, overworked or overburdened	Between Groups	14.203	6	2.367	2.219	0.040
		Within Groups	428.756	402	1.067		
		Total	442.958	408			
	Conflict with previous daily commitments	Between Gps	16.354	6	2.726	2.365	0.029
		Within Groups	463.211	402	1.152		
		Total	479.565	408			

Relationship amongst sociodemographic data, time spent in care activities and stress level

Spearman’s correlation coefficients (r) revealed that the age of caregiver had a positive correlation with time spent in taking care of the recipient (r = 0.144, p = 0.003). Age of care recipient was negatively correlated with the time spent in care activities by the caregivers (r = −0.155, p = 0.002).

Perceived stress level of carers was positively correlated with the time spent in taking care of the recipient (r = 0.157, p = 0.001), and it was negatively correlated with the number of illnesses (r = −0.185, p = 0.000). Table 23 shows the correlation coefficients amongst caregiver demographic, time spent in care activities and stress level.

Table 23: Correlation coefficients amongst caregiver demographic, time spent in care activities and stress level

		Age of caregiver	Working hours	Household income	Age of care recipient	Number of illnesses	Time spent in care activities
Working hours (weekly)	**r**	−0.098					
	p	0.143					
	n	223					
Household income (monthly)	**r**	−0.261**	0.447**				
	p	0.000	0.000				
	n	382	222				
Age of care recipient	**r**	0.116*	0.030	0.080			
	p	0.019	0.651	0.116			
	n	409	223	382			
Number of illnesses	**r**	0.153**	0.169*	−0.090	0.144**		
	p	0.002	0.011	0.080	0.003		
	n	409	223	382	409		
Time spent in taking care of the recipient	**r**	0.144**	−0.141*	−0.316**	−0.155**	0.029	
	p	0.003	0.035	0.000	0.002	0.555	
	n	409	223	382	409	409	
Total score of Kingston caregiver stress scale	**r**	−0.074	−0.103	−0.099	−0.044	−0.185**	0.157**
	p	0.136	0.124	0.053	0.371	0.000	0.001
	n	409	223	382	409	409	409

Remarks: ** Correlation is significant at the 0.01 level (2-tailed)
* Correlation is significant at the 0.05 level (2-tailed)

Workplace policy and support

A total of 186 working caregivers responded to the question on caregiver friendly policies in workplace. It is found that most of the working participants' workplace (135, 72.6%) could provide flexible work schedules (64, 34.4%), extra paid leave (35, 18.6%) e.g. family leave, unpaid leave (33, 17.7%) and others (3, 1.6%) for their employees if necessary. More than half of the employees (108, 58.0%) had experienced the benefit of flexible work schedules (65, 34.9%) and extra paid leave (43, 23.1%).

The majority of working caregivers (156, 83.9%) had no experience in receiving any unfair treatment or unapproved leave. Among 187 working caregivers, most common special arrangement made in work of caregiving were reduced working hours (67, 35.8%) and change in work schedule (68, 36.4%).

Most of the working caregivers (149, 79.6%) felt extra work stress for caregiving, and more than one-third of them had the sense of being discriminated (69, 36.9%). Table 24 shows the availability of policies and workplace situation.

Table 24: Availability of policies and workplace situation

	Employer		**Self-employed**		**Employee**		**Subtotal**		**Total**	**Missing**	**Working caregiver**
	Freq	**%**	**Freq**	**%**	**Freq**	**%**	**Freq**	**%**			
a. Availability of policies in workplace to employees											
No	2	1.1%	4	2.2%	45	24.2%	51	27.4%	186	19	205
Flexible work schedules	11	5.9%	20	10.8%	33	17.7%	64	34.4%			
Extra paid leave	2	1.1%	1	0.5%	32	17.2%	35	18.8%			
Unpaid leave	2	1.1%	2	1.1%	29	15.6%	33	17.7%			
Others	0	-----	1	0.5%	2	1.1%	3	1.6%			
Total	**17**	**9.1%**	**28**	**15.1%**	**141**	**75.8%**	**186**	**100%**			
b. Policies applied or used by participants at workplace in the last 6 months											
No	1	0.5%	3	1.6%	41	22.0%	45	24.2%	186	19	205
Flexible work schedules	10	5.4%	20	10.8%	35	18.8%	65	34.9%			
Extra paid leave	4	2.2%	2	1.1%	37	19.9%	43	23.1%			
Unpaid leave	2	1.1%	2	1.1%	26	14.0%	30	16.1%			
Others	0	-----	1	0.5%	2	1.1%	3	1.6%			
Total	**17**	**9.1%**	**28**	**15.1%**	**141**	**75.8%**	**186**	**100%**			
c. Unapproved leave or unfair treatment received due to caring in the last 6 months											
No	15	8.1%	28	15.1%	113	60.8%	156	83.9%	186	19	205
Sometimes	2	1.1%	0	-----	26	14.0%	28	15.1%			
Often	0	-----	0	-----	2	1.1%	2	1.1%			
Total	**17**	**9.1%**	**28**	**15.1%**	**141**	**75.8%**	**186**	**100%**			
d. Change or special arrangements made in work for caregiving											
No	1	0.5%	1	0.5%	19	10.2%	21	11.2%			
Change in work schedule	7	3.7%	7	3.7%	54	28.9%	68	36.4%			

Reduced working hours	7	3.7%	14	7.5%	46	24.6%	67	35.8%	187	18	205
Resignation	1	0.5%	2	1.1%	9	4.8%	12	6.4%			
Change jobs	1	0.5%	1	0.5%	9	4.8%	11	5.9%			
Early retirement	0	-----	3	1.6%	5	2.7%	8	4.3%			
Total	**17**	**9.1%**	**28**	**15.0%**	**142**	**75.9%**	**187**	**100%**			
e. Do you ever have feelings of extra work stress for caregiving?											
No stress	4	2.1%	11	5.9%	23	12.3%	38	20.3%	187	18	205
Some stress	12	6.4%	13	7.0%	90	48.1%	115	61.5%			
A lot of stress	1	0.5%	4	2.1%	22	11.8%	27	14.4%			
Extreme stress	0	-----	0	-----	7	3.7%	7	3.7%			
Total	**17**	**9.1%**	**28**	**15.0%**	**142**	**75.9%**	**187**	**100%**			
f. Do you think discrimination against caregivers is common in the workplace of Hong Kong?											
Very common	0	-----	4	2.1%	9	4.8%	13	7.0%	187	18	205
Common	7	3.7%	6	3.2%	43	23.0%	56	29.9%			
Uncommon	7	3.7%	10	5.3%	61	32.6%	78	41.7%			
Very uncommon	3	1.6%	8	4.3%	29	15.5%	40	21.4%			
Total	**17**	**9.1%**	**28**	**15.0%**	**142**	**75.9%**	**187**	**100%**			

The majority of the participants (135, 72.6%) reported that caregiver friendly policies were available in their workplace. The stress level of working caregivers between the presence (mean = 25.89, SD = 6.58) or absence (n = 51, mean = 24.80, SD = 8.68) of carer-friendly policies in workplace showed no significant difference (p = 0.358).

Many participants (141, 75.8%) had applied or used the policies in the past 6 months. The stress level of those who applied carer-friendly policies (mean = 25.50, SD = 6.66) was slightly lower than that of those who never applied for flexible or special working hours (n = 45, mean = 25.91, SD = 8.79). No significant different of stress level found between the groups applied and not applied the policy in this study.

In the meantime, a minority of participants (30, 16.1%) reported that their leave applications had been rejected or received unfair treatment due to caring. There was a significant difference in the stress level of the participants had experiences of unapproved leave or unfair treatment due to caring role (mean = 28.80, SD = 7.52) and those without such experiences (mean = 24.98, SD = 7.00). Table 25 shows the stress level of participants with different experiences in workplace support.

Table 25: Stress level of participants with different experiences in workplace support

	Workplace situation	Exp	n	Mean	SD	t	df	p
a.	Carer-friendly policies available in workplace	**No**	51 (27.4%)	24.80	8.68	-10.922	184	0.358
		Yes	135 (72.6%)	25.89	6.58			
b.	Policies applied or used by the participants	**No**	45 (24.2%)	25.91	8.79	0.335	184	0.738
		Yes	141 (75.8%)	25.50	6.66			
c.	Experience of unapproved leave or unfair treatment due to caring	**No**	156 (83.9%)	24.98	7.00	-2.703	184	0.008
		Yes	30 (16.1%)	28.80	7.52			

Care issues

A total 409 participants were asked about three open-ended questions: ‘Any concern about care issues?’, ‘Any extra stress during COVID-19 pandemic?’ and ‘Any experiences of discrimination related to care responsibility?’.

For the first question ‘Any concern about care issues?’, 336 out of 409 participants responded. Overall, 275 care issues were collected from 238 participants (70.8%). The care issues were grouped into 25 categories initially, and comparing the matrix data allowed the investigator to merge overlapping categories. In the end, 6 areas were identified as issues: feelings and emotion (70), information need (59), family and social issues (48), community resources (38), caregivers’ abilities (32) and tangible support (28). The remaining 98 participants (29.2%) had no concerns on care issues. A summary of participants’ concern on caring issues is shown in Table 26.

Table 26: Participants' concern on caring issues

Theme		Care issues	Freq	Subtotal
a.	Feelings and emotion	Lack of emotional support	17	70
		Sense of helplessness	15	
		Extremely stressful	11	
		Strong sense of loneliness	9	
		Lack of personal time	7	
		Strong sense of patient's abundance	4	
		Worry about patient's safety when he/she is alone	4	
		Worrying about own care issues in the future	3	
b.	Information need	Lack of knowledge in providing physical & psychological care	39	59
		Search for resources	12	
		Unable to grasp updating condition	8	
c.	Family and social issues	Family coherence and practical support	25	48
		Family conflict in caring issues	15	
		Role conflict	4	
		Treasuring time with patient	2	
		Improving relationship with patient	2	
d.	Community resources	Lack of community care services	23	38
		Dissatisfaction of existing services	10	
		Lack of palliative care services	5	
e.	Caregivers' ability	Inadequate ability to take care of the patient	21	32
		Tiredness and fatigue	6	
		Wish to take care of the patient at home	5	
f.	Tangible support	Not allowed to visit	12	28
		Financial difficulty	12	
		Unable to appoint maid/helper	4	
			Total	**275**

Stress related to the pandemic situation

Regarding the second question 'Any extra stress during COVID-19 pandemic?', 341 out of 409 participants answered. Overall, 372 items of stress were collected from 222 participants (65.1%). The causes of stress were grouped into 22 categories initially, and comparing the matrix data allowed the investigator to merge overlapping categories. In the end, 4 areas were identified as issues: caregiver factors (124), patient factors (102), environmental factors (91) and policy factors (55). The remaining 119 participants (34.9%) reported no extra stresses during the pandemic. A summary of extra stress during COVID-19 is shown in Table 27.

Table 27: Summary of extra stress during COVID-19 pandemic

Theme	Extra stress	Gender		At work		Subtotal	Total
		M	F	Yes	No		
a. Caregiver factors	Constraint in daily activities and change in lifestyles	5	22	9	18	27	124
	No one to take care of the recipient if infected	4	17	14	7	21	
	Tense relationship due to being confined at home	7	14	4	17	21	
	Sense of helplessness or guilty feeling for unable to perform the expected role to other family members	4	16	9	11	20	
	Worry about COVID-19 vaccination or antigen test	5	11	6	10	16	
	Increased financial difficulty or burden	3	9	5	7	12	
	Difficulty in searching for appropriate services	1	3	2	2	4	
	Unable to accompany in the last journey	1	2	2	1	3	
b. Patient factors	Increased physical and psychological burden	6	35	19	22	41	102
	Worry about the care recipient being infected	8	25	20	13	33	
	Reduced chance of peer support	1	8	4	5	9	
	Patient not following the infection precaution	3	5	3	5	8	
	Worry on the quality of patient care	2	4	2	4	6	
	Sense of loneliness	2	3	2	3	5	
c. Environmental factors	Avoiding outing and staying at home	8	27	14	21	35	91
	Availability of the specialised services in community	4	27	19	12	31	
	Concern on cleaning and hygienic issues	6	17	10	13	23	
	Difficulty to hire a helper	1	1	0	2	2	
d. Policy factors	‘No-visit’ policy	7	38	24	21	45	55
	Change in follow-up appointment and policy repeatedly	0	4	2	2	4	
	Risk of delayed radiotherapy/chemotherapy if infected	0	3	2	1	3	
	Refusal of private hospital to admit patient with fever	0	3	2	1	3	
	Total	**78**	**294**	**174**	**198**	**372**	

Sense of being discriminated

The participants also answered the third question ‘Any experiences of discrimination related to care responsibility?’. A total of 332 out of 409 participants responded to the question. A total of 310 participants (93.4%) had no experiences of being discriminated, including 12 of them expressed positive experiences in different situations. The remaining 22 participants (6.6%) reported bad experiences in different extents, which included verbal and nonverbal behaviours. A summary of the participants' bad experiences is shown in Table 28.

Table 28: Summary of the bad experiences from the participants

Theme	Bad experiences	Freq	Subtotal
Verbal	Inappropriate conversation to the care recipients related to his/her uncontrolled behavior or need e.g. coughing, use of oxygen & use of wheelchair	4	6
	Hard time from other family members	1	
	Difficulty to seek appropriate medical advice with respiratory symptoms	1	
Non -verbal	Inadequate resources & facilities in the community	6	13
	Strange and unfriendly eyesight from passer-by	3	
	Keep distance to the care recipients	3	
	Physical assaulted by a stranger who live nearby	1	
Not specified		3	3
		Total	**22**

Care responsibilities and working environment

Apart from the survey from 409 participants, 10 participants were interviewed for in-depth discussion on the effect of care responsibilities on their daily lives in different aspects. They were selected from 2 different organisations and covered different illnesses of the care recipients, ages, genders, relationships, social classes, employment statuses and places of care. The demographic characteristics of individual in-depth interview were shown in Appendix 3.

Five open-ended questions were asked during the in-depth interviews: (1) How did the carer responsibilities affect the participant's daily life in different aspects?; (2) Is your workplace culture caregiving friendly?; (3) Any caregiving benefits, programmes and policies available in your workplace?; (4) Any suggestions to help make the caring process easier for you and other caregivers?; and (5) What makes your workplace beneficial for caregiving? (Appendix 2).

Accessibility to services

Regarding care responsibilities, three major areas, namely, accessibility to services, caring roles and role conflicts and self-development, were mostly encountered by the participants. The participants reported that they had difficulties searching for appropriate services at the onset of illness. Public education and related information were inadequate in general. The participants had no knowledge of being eligible to apply for government allowance, and this situation caused extra financial burden. Internet searching was the most common and effective way to locate different resources. Apart from it, asking the doctor's advice, seeking information from medical social workers and cancer patient resource centre were commonly adopted. In general, the services for elderly care were easier to locate than the resources for cancer persons. The participants expressed their concerns in different ways.

> *'I wish to know the availability of the services, especially the medical services, given that I could not find the answers from books'. (Case 1)*
>
> *'At the beginning, special services were unnecessary for my father because his medical condition is generally stable. As his general condition deteriorated, he was admitted to the hospital. His doctor suggested that my father was not fit for operation, but hospice service would be more suitable. My father searched for a hospice service by himself because he had medical background. However, communicating with him after he was admitted to the hospital was difficult due to the "no-visit" policy at that time. His energy level was lower than before. He had increasing tiredness and sleepiness. Communication via phone calls or text messages was no longer effective because I was afraid to disturb his rest. Eventually, my father was transferred to a private hospice for comfort care and his quality of life had much improved since then'. (Case 5)*
>
> *'I have been fortunate enough to be able to find social workers to help. Otherwise, it could be very difficult for me to look for services offered by the government'. (Case 7)*

Caring roles and role conflicts

Some of the participants reported increased family conflict during the process of taking care of persons with advanced disease due to the change in daily routine and lifestyle. Family members were required to learn new skills to cope with the care recipient's needs. Many caregivers had a strong sense of time pressure when leaving the care recipient alone at home. A mother of an advanced-illness person shared that she felt guilty to another child given that she had put most of her effort and energy to the sick child and neglected the needs of her younger daughter who was physically healthy, even if she was a young child at that time. Several participants reflected that their temper might change after the care recipients became ill due to the adjustment problems, which increased the difficulty in effective communication.

In the meantime, rapid deterioration of physical condition caused the previous learnt skills to become inadequate to handle the situation and caused the family members to become exhausted. The participants expressed their concerns in different ways.

> *'I feel unfair to my daughter who was only 2 years older than my son. I had less focus on her needs and had given inadequate care to her'. (Case 2)*

> *'My father had move to my apartment when his illness became more serious. Since then, I had learned more skills for his daily needs, such as cooking, on which I had no knowledge before. The situation worsened when my father started to lose his appetite. I had to complete a lot of unpacking, as well as daily housework, cooking and reorganising. I felt completely overloaded at that period even if I was free from work at that time'. (Case 5)*

Self-development

Most of the participants reflected that further education and career advancement had been difficult for them. Most of them did not have time to attend any study or interest classes considering that no one can help relieve or replace their caring role temporary. One of the participants reported that she can manage a short course for relaxation at the meantime. However, it was seriously affected by the caring role, and thus, she had to quit the class eventually. The participants voiced out their concerns in different ways.

> *'I enrolled in a computer course in the past, but I had cancelled it afterwards because nobody could help take care of my son during that time'. (Case 2)*

> *'My freelance job had been affected in a certain extent. My situation might be better than those with regular full-time job'. (Case 5)*

> *'Caring had seriously affected my education and employment. I used to be a merchandiser and needed frequent travels because of the job nature. One of the major reasons causing me to quit my job was that I could not solely rely on the maid to take care of my father.' (Case 9)*

Workplace culture and caregiving-friendly policies

The second question asked whether the participant's workplace culture is caregiving friendly. Regarding workplace culture, some of them expressed that they have a supportive supervisor and co-workers, but not all of them have such a good experience. One of the participants reported that he learnt from some of his friends that some supervisors were not helpful and even threatened the employee for the risk of termination.

A total of 10 participants reported no policies for caregivers. They only benefitted from the caring attitudes from good people. Some of the participants' supervisor allowed flexible working hours for them. Their colleagues also offered help in good faith on volunteering basis. On the contrary, some of them reported difficulty in applying for annual or urgent leave to attend to follow-up appointment with their family members.

The third question asked regarding availability of any caregiving benefits, programmes and policies in the participant's workplace. All the working participants reported neither specific policies nor build-in system in their workplace to facilitate caring roles. Unnecessary tension and conflicts amongst health care professionals and the family members increased due to the poor communication without direct conversation with the health care professionals. Family members need to find extra time to revisit the clinic for further clarification even when the health care professionals had explained the details to care recipient and other older family members before.

Common barriers and possible enhancement

The fourth question was 'Any suggestions to help make the caring process easier for you and other caregivers?'. During the interviews, three main areas for improvement in the caring processes, namely, tangible support, leave arrangement and use of technologies, were identified.

Tangible support

Common problems encountered by caregivers were difficulties in daily care and transportation. Door-to-door transportation for frail people was highly demanded. The participants shared their experiences in different ways.

> *'Lifting a bedridden within a small space living environment was never an easy task for caregivers. Bringing the bedridden to their medical appointments was very inconvenient'.* (Case 1)
>
> *'I experienced increasing difficulty in transportation to hospitals for the follow-up appointment of my wife. I was once told by a nurse from the Methodist Centre that a nurse can be arranged to visit my home for blood taking and collection with the doctor's prescription. In reality, my wife had been admitted to the hospital before I had a chance to use such a service due to the further deterioration of her condition'.* (*Case* 6)

In the financial aspect, most of the participants could get the government support for basic medical expenses, but not all medications were covered. Some of them shared that the extra financial burden mainly were the new anti-cancer drugs which were not covered by the government and the increased consumption of personal care accessories and diet supplement. The participants shared their experiences as follows.

> *'I was extremely worried about the treatment cost when my wife started immunotherapy given that it was very expensive. Each dose costs around HKD$40,000, and 17 doses had been given within 2 years'.* (Case 6)
>
> *'Expenditure for napkin and various supplements, such as Vita Green, fish oil pill, Peaceful Palace Bovine Bezoar Pill, ginseng and chicken Essence, increased. Whenever my father saw new healthy supplements in advertisement, he would demand them repeatedly'.* (Case 7)
>
> *'I am fine financially because my father's case (degenerative illness) has been followed up from the government's clinic and I find the price of medication for him reasonable and satisfactory. Unlike my mother's situation, she died of lung cancer several years ago; her medication was categorised under self-financed items and was very expensive'.* (Case 9)

Leave arrangement

A participant reported difficulty in applying for a leave to accompany the family care member in an important follow-up appointment. Most of the young and educated family members belonged to the working class. They had difficulty accompanying the family member to attend to important medical consultation, which was a good chance to have better understanding of the person's disease progression and updated treatments.

The respondents suggested that family or unpaid leave for attending medical consultation with other family members and relevant ordinance and legislation can be introduced, which can help enable the family members to attend important follow-up appointment with the care recipients, such as explanation of the disease progress and discussion of treatment options. All of these can benefit from flexible working hours.

Use of technologies

Most of the participants reflected that online medical consultation and telemedicine may help relieve the pressure of the caregiver to bring along frail persons to a hospital or clinic for follow-up appointment. In the meantime, some of them expressed that use of web camera could ease their worries to ensure family members were fine and under the care of good hands, especially during the lockdown period in the pandemic situation. The participants expressed their ideas in the following ways.

> *'I think telemedicine is still unpopular and not friendly in Hong Kong. Under the pandemic situation with a demanding virus testing and vaccination policy, hospital visit for a follow-up medical appointment was even more challenging and tiring. Some essential physical examination should be kept, but other non-urgent medical follow-up appointments and consultations should be encouraged using telemedicine to help patients reserve energy away from unnecessary travelling and long hours of waiting at the hospital."* (Case 5)

> *'As my wife's general condition worsened and she started to have difficulty in walking, we chose to take a new type of hybrid taxi, which is larger in size and has a more spacious and comfortable cabin for her and her wheelchair. If a web camera for telemedicine is available, then my wife do not need to go to the hospital in person because she could barely walk at the later stage'.* (Case 6)

> *'Household video camera or closed-circuit television has been useful for me in keeping an eye on my father's situation at home when I am away. It gives family members and the patient an increased sense of security'.* (Case 9)

For the care recipients living at home, the participants shared that information search from the Internet and the availability of home-used medical equipment was important in their experiences. Advanced technologies and equipment for the patient's care are important to ease the care process at home, such as halters, bathing equipment, air mattress and special applicants. The participants shared their experiences as follows.

> *'Having better halters and lifting device would be more convenient, especially for home caring. Having a portable oxygen concentrator of smaller size would also be beneficial'.* (Case 3)

> *'I believe that bathing equipment that can prevent water spillage when bathing my wife in the bathroom would be helpful. Lifting my wife into the bath tub for shower was difficult, and therefore, she would normally sit on the toilet for shower and water would spill all over the place'.* (Case 6)

> '*I believe that household video camera or closed-circuit television would be useful for me to ensure my father's safety when I am away from home'.* (Case 9)

> *'I could do online shopping with delivery for the medical necessities of my father, such as his oversized adults' napkins and long dressing applicators for medical use. These items are difficult to locate in physical shops and pharmacy. Online shopping for personal care and medical use items could save a lot of my time'.* (Case 10)

Preferable workplace environment

The last question was 'What makes the participant's workplace beneficial for caregiving?'. The personal experiences of the participants are positive in general. They suggested that family or unpaid leave for attending medical consultation with other family members can be considered. One of the participants pointed out that overall workplace culture might not be caregiving friendly in his experience. The participant expressed his experience and expectation in the following way.

> *'I have nice supervisors, and they were very understanding. They even encouraged me to apply for unpaid leaves to spend more time with my father because one of my supervisors had personal experience as a carer to an end-stage patient before. I am very fortunate that my personal experience was pretty good. However, I learnt from my pharmacist friend and other patients that they had very bad experience. In particular, most of their organisations were not helpful and their bosses were unsupportive and even cynical in some cases. They failed to apply for unpaid leaves and were even threatened by the possibility of termination of work contract. The general situation in Hong Kong regarding caregiving-friendly workplace culture was unsatisfactory for me'.* (Case 4)

7. Discussion

Background information of caregivers

The findings showed that most of the caregivers in this study were female (70.7%) rather than male (29.3%). Most of the caregivers were aged over 50 years old (75.3%) and married (67.5%). The phenomena reflected that not only the care recipients were aging but also the caregivers. Half of them were with higher diploma level or above (51.9%) and were taking care of their parents or parents-in-law (56.7%). Their health status was largely healthy as they reported neither physical disability (95.4%) nor having long-term illness (63.6%), and their self-evaluated health was average and above (75.0%).

Amongst the caregivers in this study, 205 were at work and 204 were not at work. The 205 working caregivers included employers (8.8%), self-employed persons (18.0%) and salaried employees (73.2%). More than half of them (62.0%) were working over 40 hours per week. The results similar with the local findings that median weekly working hour for male and female employees were 42.0 and 44.3 in Hong Kong (Census and Statistics Department, 2021).

For the caregivers, they were unemployed persons (6.4%), housekeepers (38.2%), retired persons (54.4%) and students (1.0%). High percentage of the caregivers was retired and aged persons.

Background information of care recipients

Most of the care recipients were aged over 60 years old (79.7%). The distribution of male (42.8%) and female (57.2%) was relatively even compared with the distribution of caregivers. Major diagnoses were advanced cancer (38.6%), end-stage organ failure (17.1%), degenerative illness (40.6%) and others (3.7%). Other illnesses included uncontrolled diabetes mellitus, severe chronic obstructive pulmonary disease and psychiatric illness. Advanced cancer and end-stage organ failures were common terminal illnesses. Degenerative illness could be a life-limited condition with relatively longer and slower deteriorating process.

More than half of the care recipients (51.4%) suffered from at least three kinds of illnesses simultaneously. Multiple diseases might further complicate the physical conditions and increase the complexity of care in daily life. Multiple illnesses and polypharmacy cause complex drug interaction, and the presentation symptoms might be masked by other effects and clinical features due to multiple illnesses and pathophysiological changes. The combination of diseases and treatment effects of individual care recipients were no longer straightforward. This situation further increases the caregiver’s burden, the sense of inadequacy and lack of knowledge to manage the patient’s condition.

Regarding self-care ability, 35.2% of the care recipients were totally dependent, and 28.4% of them had a great difficulty in self-care. Nearly half of the care recipients (49.6%) lived with the caregiver, and one-third (35.7%) lived at their own home as usual in the past 6 months. For those persons living alone with progressive deteriorating general health, they run the risk of increase sense of insecurity and anxiety, decrease mobility and sense of control. Technological advances would be made to help them to overcome the problems and ease the individuals’ worries about the risk of the care-recipients, such as use of monitoring and alerting system.

Time spent in taking care of recipients

Gender difference

The findings of this study showed that the caregivers had spent 1 hour to 168 hours (24 hours for 7 days) per week in their care recipients. The mean was 40.60 hours, and median was 21 hours per week.

No significant difference was found between different genders in time spent to the main care recipients. The results showed that female caregivers (mean = 42.02, SD = 43.29) spent longer hours in care than male caregivers (mean = 37.16, SD = 42.09).

Difference in major illness groups

A significant difference was observed between major illness groups and time spent to the care recipients (F = 3.127, p = 0.026). The results revealed that caregivers of advance cancer patients (mean = 47.29, SD = 48.57) spent longer hours than degenerative illness group (mean = 38.89, SD = 37.99), end-stage organ failure group (mean = 31.65, SD = 38.30) and other illness group (mean = 24.27, SD = 40.61). Tables 9 and 11 indicate the time spent in taking care of recipients in different major illness groups and the relationship of time spent and disease group representatively.

The abovementioned figures show that the duration of care was longer when the illness was more serious. Advance cancer is always a tragedy and deteriorates rapidly in the last few months. The symptom development and self-care abilities might be changed drastically. The caregivers had difficulty adapting to the patient's physical change and cope with the psychological needs within such a short period of time. For degenerative illness, the patient's condition was changing gradually and even in terms of years. Although the caregivers could learn different caring skills step by step, the patients' dependence always increases gradually. The caregivers would be exposed to a long process of care with the gradual increase in the patient's dependence. This situation can cause compassionate fatigue and emotional burnout easily. In end-stage organ failure, the care recipients were physically weak and had fluctuation in energy levels subject to their stages of disease. The rest of other illnesses were uncontrolled diabetes mellitus, severe chronic obstructive pulmonary disease and psychiatric illness. All these illnesses might inconsiderably affect the patient's activities of daily living, except during the moment of acute exacerbation. The care recipients in this group may need more psychological support and adjustment to normal life rather than hands-on physical care. Therefore, less physical efforts should be exerted on these groups of patients.

Difference in employment status

A significant difference was found between economic activity status groups and time spent to the care recipients (F = 9.190, p = 0.00). The results revealed that the caregivers of not-at-work group (mean = 54.33, SD = 50.43) spent much longer hours in care than at-work group (mean = 26.93, SD = 27.97). Tables 10 and 11 indicate the time spent in taking care of recipients by economic activity status and whether at work and the ANOVA table for time spent by economic activity status respectively.

The results revealed that housekeepers (mean = 61.45, SD = 53.54) and unemployed persons (mean = 60.00, SD = 41.51) spent more time in taking care of the recipients than retired persons (mean = 49.46, SD = 48.98%) and students (mean = 10, SD = 0.00) in the not-at-work group. In the housekeeper and unemployed groups, 60 care hours per week, which is equal to

8.5 hours per day in average, were equivalent to working hours for a full-time job without any holidays. For the retired persons, their energy level may be lower than that of unemployed persons and housekeepers, who might be relatively younger with higher energy levels. The results reflected that students might be one of the caregivers but were unlikely a main caregiver considering that they may be engaged by the school works and studies. In the Chinese community, most of the parents prioritise the academic performance of their children. Thus, the time spent and the number of caregivers in the student group was relatively low. They usually will only be involved in the very last moment when their loved one is very ill and near the end of their life.

In the at-work group, self-employed persons (mean = 35.22, SD = 38.54) spent more time in taking care of the recipients than employees (mean = 25.17, SD = 24.79) and employers (mean = 24.56, SD = 25.95). Most of the self-employed persons had ease in arranging their works more flexibly than the employers and employees who mostly have fixed work schedule. In the self-employed group, the participants spent 35.22 hours per week in average, which is equal to 5 hours per day for 7 days a week. The situation reflected that they need to spare another 5 hours to tend to their loved one on top of the normal working hours and duty. Otherwise, they need to sacrifice their usual working time by decreasing their input and effort in their business, which may further decrease their income and increase their financial burden simultaneously.

Perceived stress level

Gender difference

The findings of this study showed that the mean and standard deviation of caregiver stress level was 25.85 and 7.68 respectively. No significant difference was found between different genders in their stress level. The results showed that female caregivers (mean = 26.17, SD = 7.76) had higher stress level than male caregivers (mean = 25.09, SD = 7.46). The higher stress level may be related to the pre-existing stress from multiple roles as women.

Major illness groups

A significant difference was found between disease groups in several items of stress level. They were ‘Change in relationship with spouse or relatives’ (F = 4.530, p = 0.004), ‘Conflicts with family over care decisions’ (F = 5.011, p = 0.002) and ‘Conflicts with family over the support you are receiving’ (F = 6.387, p = 0.000). The perceived stress in other group (mean = 27.67, SD = 8.89) was higher than that in degenerative illness group (mean = 26.43, SD = 8.32), advanced cancer group (mean = 25.54, SD = 6.84) and end-stage organ failure group (mean = 24.86, SD = 7.75). Tables 20 and 22 indicate the stress level of various major illness groups and the relationship of the stress items and major illness groups respectively.

Undoubtedly, all caregivers would like to tend to their loved ones and provide the most suitable environment and support to them. The problem is that different people may have different perspectives and point of views in handling a same situation. Family dynamic takes an important role in the family relationship and family decision. It not only could improve mutual understanding and support but also could create more conflicts amongst the family members due to different values, lifestyles, preferences and available resources of each other. Many different kinds of treatments are available for advance cancer illness like chemotherapy, radiotherapy, target therapy, immunotherapy and alternative therapy. Care recipients, main caregiver, other family members and even different health care professionals may hold different views in the treatment options. The process of making decision can create different kinds of conflicts related to the effectiveness of the treatment, involvement of different family members during the process, the patient's preference, financial support and other resources involved.

Surprisingly, caregivers caring for people with other illnesses perceived higher stress level (mean = 27.67, SD = 8.89) than the advanced cancer, end-stage organ failure and degenerative disease group. The phenomenon indicated the possibility of inadequate support and resources available for people suffering from other kinds of illnesses in Hong Kong.

Employment status

A significant difference was observed between economic activity status groups and two sub-items of level of stress. The items were 'Feelings of being overwhelmed, overworked or overburdened' (F = 2.219, p = 0.040) and 'Conflict with previous daily commitments' (F = 2.365, p = 0.029). The results revealed that the caregivers of at-work group (mean = 25.98, SD = 7.49) reported similar stress level to overall not-at-work group (mean = 25.72, SD = 7.88). Within the at-work group, three subgroups were self-employed (mean = 27.39, SD = 7.79), employee (mean = 25.90, SD = 7.56) and employer (mean = 23.83, SD = 5.84). Within the not-at-work group, four subgroups were housekeepers (mean = 27.10, SD = 7.86), retired persons (mean = 25.05, SD = 7.95), unemployed (mean = 24.77, SD = 6.18) and students (mean = 16.00, SD = 1.41). Tables 21 and 22 indicate the stress level of caregivers in various economic activity statuses and the ANOVA tables for selected stress items by economic activity status group respectively.

The results revealed that self-employed (mean = 27.39, SD = 7.79) and housekeepers (mean = 27.10, SD = 7.89) had higher stress level. In the self-employed group, caregivers could manage to spend more time to take care of the recipients with flexible arrangement. At the same time, self-employed persons are likely running a small business by them. Less effort and less input indicate less productivity and decrease the ability to generate of income directly. They might need to sacrifice some of the earning opportunities to spare precious time to tend to their family members. On the contrary, finding someone who could replace the usual works of self-employed persons is difficult. They may need to squeeze other time to complete the task apart from tending to the care recipients. Time constraint, financial stability and other commitment can contribute to the carer stress. Similar to the situation in housekeepers, they can manage their time flexibly, but it does not mean that they have more time to complete the task. One of the ways is to shift their leisure time or rest period to tend to the care recipients.

Relationship amongst caregiver's demographic characteristics, time spent in care activities and stress level

The results of this study revealed that the stress level of the caregiver was positively correlated with the time spent in taking care of the recipient (r = 0.157, p = 0.001). The caregivers who decided to spend more time to take care of their loved one are likely more concern on their quality of life and quality of care. Thus, the caregivers would have higher stress level and exert more efforts to the patients.

Time spent in taking care of recipients was positively correlated with age of caregiver (r = 0.144, p = 0.003) and negatively correlated with monthly household income (r = −0.316, p = 0.000) and age of care recipient (r = −0.155, p = 0.002). Aged caregiver would spend more time in the care issues. They might believe that spending more time with their loved one when they are still able to do so is important. For the monthly household income, lesser household income can be obtained with more time spent in the care issues, which might reflect that the level of care recipients' needs was similar. However, lower family income group intends to take care of the persons by themselves instead of hiring a helper or maid in daily activities. When people put their time in the non-money-making areas, such as care of their loved one, they need to put less effort in money-making area, such as their career. The results revealed that lesser time of care would be given to the older care recipients. It may relate to the severity of illnesses, and people intend to treat the aged person with illnesses as part of the normal aging process and the supporting services for elderly care was relatively easy to locate in the community.

Extra stress from workplace environment and pandemic situation

The findings of this study revealed that most of the employed participants (79.6%) experienced extra work stress for caregiving, and more than one-third of them (36.9%) opined that discrimination against caregivers is common or very common in the workplace of Hong Kong. On the other hand, Table 25 revealed that caregivers who had applied the care-friendly policies in workplace were slightly less stressful than those who never applied the care-friendly policies. In view of the caring issues for the working caregivers, a care-friendly environment is worthy to be developed. Some of the participants of the in-depth discussion suggested that flexible working hours and family leave for accompanying the patient to attend some important medical appointments would be helpful. A considerate and caring environment would help the working caregiver become more relieved and able to focus on his or her works after the family issue had been settled and further improve his or her working relationships.

In the meantime, 222 participants indicated that they had extra stress during the pandemic situation. Four major areas were identified, namely, caregiver, patient, environmental and policy factors. The most common stressors were '"No-visit" policy', 'Increased physical and psychological burdens of care recipients' and 'Possibility of care recipients is being infected'. The participants reflected that their worries were increased by the constraint in daily activities and the absence of someone to replace their role in taking care of their loved one if they would be infected and need mandatory isolation. If no appropriate persons would tend to the care recipients for a certain time, then mood and general health condition of the care recipient would be further affected. This aspect was talking about not only the physical care but also the psychological support to the care recipients, especially when their loved ones were in their very late stage of life. One of the family members expressed that her father believed that he would die lonely in a strange environment because of the 'no-visit' policy and became very depressed despite he was not being infected. Most of the caregivers intend to keep their loved one at home as much as they can but worry whether they could provide a good care to their loved one at home. Summary of extra stress during COVID-19 is shown in Table 27.

8. Recommendations

The abovementioned discussion revealed that self-employed and housekeepers experienced higher stress level. Caregivers who were female, unemployed, housekeeper and caring for people with advanced cancer were prone to spend more time in the care issues. Moreover, concerns regarding the future care needs of care recipient caused higher stress level amongst different sources of stress items. The overall stress level was positively correlated with the time spent in care activities. The severity and sources of stress of the caregiver in different stages of illnesses covered information, psychological and social needs.

Informative needs

Service access

Recommendation 1 - Hospital Authority, Department of Health, Social Welfare Department or NGOs to develop a comprehensive website or app as a reliable platform for the available services and enhance the availability of community resources.

Information needs can be addressed by the Hospital Authority, Department of Health, Social Welfare Department or NGOs in providing appropriate information for various public and private services in different stages, household equipment, transportation services for care recipients and supplementary nutrition supply and consumables for daily care.

The participants reported that they spent a lot of time to search for suitable services for their family members. Some of them expressed that they had missed the most appropriate time for relevant services because of the difficulty to search for the related services. Using more technology for information and resource searching can help the caregivers locate the relevant information earlier and become aware of their choices to reduce unnecessary stress. Further developing a comprehensive website or apps as a reliable platform for the available services may help. The availability of community resources also takes an important role to relieve the caregiver stress.

Household equipment and transportation

Recommendation 2 – Introduce the concept of household equipment libraries by government department (e.g. Electrical and Mechanical Services Department) or NGOs with installing and maintenance services to suit the needs of the care recipients in the rapid change of physical conditions and ensure the safety operations.

Energy levels of care recipients always showed a decreasing trend. The speed of deterioration may be gradual or sharp depending on their disease progression. User-friendly home applications and disease specific equipment become one of the necessary elements to improve the quality of life of the care recipients and the caregivers. Examples are home lifting devices, bathing equipment, oxygen concentrator and home care support. The caregivers could learn how to tend to the care recipient at home with increased sense of security through empowering them. The caregivers would be more relieved and settled in physical and psychological aspects by improving their condition and comfort care.

In reality, not all the equipment can purchase and install within a short period of time. These processes may take weeks to months such as for electric lifting devices and electric beds. A timely services to address the sudden needs of care recipients and family caregivers could ease their burden from the workload of daily care activities.

Recommendation 3 – Increase the supply of special wheelchair taxi, accessible hire car and private non-emergency ambulance booking services by NGOs and commercial partners. Further develop telemedicine services by Hospital Authority for patients with relatively stable condition to attend follow-up consultations.

Many caregivers reported that transportation is one of the major difficulties frequently encountered in their daily care. For a wheelchair-bound person, special wheelchair taxi is difficult to book. Even if they had booked the transportation services successfully, they have no control in the return time because of the long queue of the medical consultation and medication even with appointment. For bedridden people, they may only able to use non-emergency ambulance services, which should be booked by the Hospital Authority. Some of the family caregivers are willing to pay for a better service, such as use of private ambulance services. Such private service is not only costly but also very limited in the market. Supply of special wheelchair taxi, accessible hire car and private non-emergency ambulance services should be further increased to meet the need of people with advanced illness, and information can be consolidated in the proposed comprehensive website or app.

Telemedicine can be another option for medical consultation of the people who have difficulty to attend to out-patient appointments with relatively stable condition. It is strongly recommended that Hospital Authority can expand telemedicine service to non-urgent follow-up medical appointments, especially after the pandemic, so that caregivers and patients benefit fewer transportation problems and only have need-to-have hospital visits.

Psychological needs
Recommendation 4 – Early referral of palliative home care services and set up a designated hotline operated by a group of experienced home care nurses and social workers under Hospital Authority with the access of clinical management system and electronic Health Record Sharing System, which allow them to have better understanding of patient's updated medical condition and provide the most appropriate advice.

Some of the caregivers mentioned that they had difficulty handling the emotional reactions of the care recipients. Psychological interventions included introducing effective coping skills for the caregiver and improving their understanding of the normal grieving process of the care recipients and the caregivers. Family conflicts related to the decision and care support can be avoided through more effective communication and by improving the awareness of the caregivers about their emotion and the underlying reasons of the care recipient's behaviour. Universal screening of the needs of care recipients and caregivers for early referral to professional counselling services might help improve the situation before it worsens.

Early referral to palliative home care services for a comprehensive assessment, including physical, psychological, social, spiritual and cultural needs, were important for early identification of the care recipients' and the family caregivers' needs. The prerequisite is the patients and the family caregivers able to access the palliative care services.

A group of well-trained professionals who have adequate knowledge about the specific groups of advanced illness and the emotional needs of the patients and family caregivers can operate a hotline and provide ad hoc support. Again, the information can be consolidated in the proposed comprehensive website or app.

Social needs
Availability of skilful helper

Common social needs of the caregivers included the availability of a skilful helper, culture of caregiver-friendly working environment and specific resources for the groups of less common disease. There are limited quality trained helpers for the advanced illness, most of the trained helpers mainly focus on the needs of frail elders. Different NGOs provided training course and suited the needs of the Residential Care Homes for the Elderly and the Residential Care Homes for person with Disabilities. Only very limited NGOs provided specific training for the carers of advance illnesses for their organization needs.

Recommendation 5 – Increase qualitied institutes, such as NGOs, to provide appropriate training to both formal and informal carers of the patient with advanced illnesses.

Some of the participants mentioned the extreme difficulty in finding a quality and suitable person to take care of their loved one. Increase the supply of quality home helpers specifically trained for the care of persons with advanced illness at home settings can be considered. Examples of these skills are basic vital sign checking, feeding technique, bathing at home, passive exercise and being sensitive to the patient's condition changes. Disease progression of different illnesses varies, and complexity increases with multiple illnesses. Day respite care can be considered in earlier stage of advanced illnesses with good transportation support. Skill training tailored to individuals in day care centre can be one of the subtle ways to empower family members and existing helpers by enhancing their care skills.

If the care recipients' physical condition further worsens, frequent transportation may not suitable for them in late stage of advanced illness due to the gradually deteriorating energy level of the care recipients. Some of the caregivers may fail to grasp the care skills within a short period of time to suit the needs of their family members. The stability of the care worker also helps develop a good client–worker relationship, which can benefit the caregiver and the care recipient by improving understanding of the care recipient's needs and being more sensitive to the condition change. It can ease the burden of the caregivers and enable them to have time for their daily works without worrying about the care recipients.

Caregiver-friendly work environment

Recommendation 6 – Labour Department should set guidelines for employers to build a caregiver-friendly workplace. The Government should take the lead and be a role model of developing policy for the caregiver-friendly workplace.

Some participants mentioned that they had a supportive supervisor and colleagues, which allowed them to have flexible working hours and hand over their job in some occasions. Those people usually had experiences in taking care of family members with serious illness in the past. They know the difficulty of a working caregiver and are willing to offer help as much as they can. In a long run, developing a specific policy for the caregiver-friendly workplace might benefit the organisation. All organizations have their own responsibilities to develop a caregiver-friendly work environment and promote an organizational culture to address the needs of their workers who have the role of caregiving patients with advanced illness in their families. Measures for nurturing a caregiver-friendly work culture includes educating the frontline managers about the common challenges facing by the caregivers; gathering the experiences and views from colleagues, especially who had taken / are taking care patients with advanced illnesses, developing a user-friendly guide; providing a pool of information about the available resources in the community; and facilitating the ad hoc support in case of urgency.

Developing a system for the justification of flexible working hours, work from home arrangement and family leave for employees to attend important follow-up appointment with their care recipients would help relieve the psychological burden of the workers. It could further increase staff morale, attract quality workers, decrease employee turnover, increase productivity and retain talented loyal workers. The Government should take the lead to develop the policy and system for the caregiver-friendly workplace.

Special concern on less common diseases

Recommendation 7 – Separate the queue for care services for patients with less common advance illnesses and life expectancy less than one year

A miscellaneous group of caregivers in this study perceived higher stress level than other disease groups, including advance cancer, end-stage organ failure and degenerative illness. The miscellaneous group was mainly composed of uncontrolled diabetes mellitus, severe chronic obstructive pulmonary disease and psychiatric illness. Nowadays, most of the community resources focus on the elderly care because of the aging society. Several serious illnesses have active disease progression. Patients with these illnesses may fail to enjoy the standard community resources given that the available services may not suit their needs. For example, the rehabilitation programmes for people with mental illnesses are totally different from those with physical illnesses.

Most of the community resources are illness specific and age orientated. Some of the rare illnesses or relatively younger patients unable to enjoy the existing services and their burdens are even heavier. Separate resources for that particular groups of patients and caregivers may help. Those patients with advanced illnesses usually have shorter life expectancy e.g. in terms of months. They may not have the time to wait for usual care and attention home before they passed away. A special queue for the care and attention homes with skillful workers specific for serving patients with more physical symptoms and rapid deterioration are expected for this particular group of patients.

9. Limitation and further study

The findings showed that the stress level of miscellaneous disease group was higher than that of other disease groups. The miscellaneous disease group included some advance chronic diseases and psychiatric illnesses. Which of the disease groups induced a high level of carer stress was uncertain. Future works could explore the stress and needs of caregivers in caring for people with chronic and mental illnesses.

10. Conclusion

Caregivers of people with advance illnesses are facing different challenges in terms of balancing work with caregiving duties. In this study, the average time spent in caring for family members with advance illness is 40.6 hours per week. Caregivers who were female, not-at-work, and caring for people with advanced cancer were prone to spend more time in the care issues. The results show a significant correlation between the time spent in caregiving and the level of stress. The stress levels in self-employed and housekeeper groups are higher than those in others. Caregivers with successful experiences in applying for a leave for care-related aspects are prone to have less stress. Therefore, addressing the needs of caregivers in different aspects, including information, psychological and social aspects, is important.

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12. Appendices

Appendix 1: Caregivers Stress Questionnaires - Chinese version

Appendix 2: Caregiver Stress Interview Guide

Appendix 3: Demographic characteristics of individual in-depth interview

Appendix 1: Caregiver Stress Questionnaires – Chinese version

明愛專上學院

照顧者壓力問卷

甲部：照顧者資料				
1. 患病家人是你的：(可選多項)	□ 成年子女	□ 兄弟姐妹	□ 配偶	
	□ 父母/岳父母/老爺/奶奶	□ 祖父母	□ 其他 ______	
2. 過去的 6 個月，你需要同時照顧多少個患病家人？	□ 1	□ 2	□ 3 或以上	
3. 年齡	□ 30 歲或以下	□ 31-40 歲	□ 41-50 歲	
	□ 51-60 歲	□ 61-70 歲	□ 71 歲或以上	
4. 性別	□ 男	□ 女		
5. 婚姻狀況	□ 單身	□ 已婚	□ 分居	
	□ 離婚	□ 寡婦/鰥夫		
6. 教育程度	□ 小學或以下	□ 初中	□ 高中	
	□ 文憑/證書/副學士	□ 大學學位	□ 碩士或以上	
7. 個人身體狀況	**(a)** 殘疾	□ 沒有	□ 有	
	(b) 長期病患	□ 沒有	□ 有	
8. 自我評估健康狀況	□ 健康良好	□ 一般	□ 有一些健康問題	
	□ 有嚴重健康問題			
9. 現時就業狀況	□ 僱主	□ 自僱	□ 受薪僱員	□ 待業中
	□ 料理家務者	□ 已退休	□ 其他 (請註明)______________	
10. 每星期平均工作時數 (如現時在職)	□ 少於 10 小時	□ 10-19 小時	□ 20-29 小時	
	□ 30-39 小時	□ 40-49 小時	□ 50 小時以上	
11. 每月家庭總入息 (包括薪金、投資、政府津貼及家人經濟支援)	□ 沒有 (港幣 $0)	□ 港幣 $1 – 4,999		
	□ 港幣 $5,000 – 9,999	□ 港幣 $10,000 – 14,999		
	□ 港幣 $15,000 – 19,999	□ 港幣 $20,000 – 24,999		
	□ 港幣 $25,000 – 29,999	□ 港幣 $30,000 – 34,999		
	□ 港幣 $35,000 – 39,999	□ 港幣 $40,000 – 49,999		
	□ 港幣 $50,000 – 59,999	□ 港幣 $60,000 – 69,999		
	□ 港幣 $70,000 – 79,999	□ 港幣 $80,000 或以上		
12. 職業	□ 經理及行政级人員	□ 專業人員		
	□ 輔助專業人員	□ 文書支援人員		
	□ 服務工作及銷售人員	□ 工藝及有關人員		
	□ 機台及機器操作員及裝配員	□ 非技術人員		
	□ 其他 (請註明) ________________			

乙部：主要照顧對象資料

1. 在過去的 6 個月，誰是你的主要照顧對象(花最多時間 / 精力的照顧對象)？

□ 兒子 □ 女兒 □ 兄弟 □ 姐妹 □ 丈夫 □ 妻子
□ 父親 □ 母親 □ 岳父 □ 岳母 □ 祖父 □ 祖母
□ 老爺 □ 奶奶 □ 其他 (請註明)________________

2. 年齡	□ 20 歲或以下 □ 21-30 歲 □ 31-40 歲 □ 41-50 歲 □ 51-60 歲 □ 61-70 歲 □ 71-80 歲 □ 81 歲或以上
3. 性別	□ 男 □ 女
4. 主要嚴重疾病	□ 晚期癌症 □ 晚期腎病 □ 晚期心臟衰竭 □ 晚期肝衰竭 □ 其他器官衰竭 □ 晚期知認知障礙 □ 肌肉萎縮症 □ 其他 (請註明)__________________________
5. 其他疾病	□ 沒有 □ 慢性疾病 (請註明)______________________ □ 殘疾 □ 近期接受手術 (請註明)__________________
6. 主要照顧對象的自理能力	□ 完全可自我照顧 □ 只有少許困難 □ 有很大困難 □ 完全需要依賴別人照顧
7. 疾病種類數目	□ 1 □ 2 □ 3 □ 4 □ 5 □ 6 或以上
8. 在過去的 6 個月，主要照顧對象主要居於：	□ 醫院 □ 護理、安老或其他院舍 □ 如常與本人同住 □ 為了方便照顧，暫遷往本人家中居住 □ 並非與本人同住，而是一直居於他/她在自己家中 □ 其他 (請註明)__________________________

丙部：過去的 6 個月主要照顧對象所需的協助

1. 請在下列選項中選擇您過去的 6 個月為主要照顧對象提供的協助 (可同時選擇多個活動)

□ 協助行動 □ 協助用餐或預備食物
□ 協助洗澡和穿衣 □ 失禁護理
□ 協助復康訓練 □ 協助認知訓練
□ 協助購物 □ 護理照顧 (如：洗傷口、處理造口、打針及抽痰等)
□ 陪伴到醫院、診所覆診 □ 處理家務 (如：日常清潔、更換床單等)
□ 情感支援 □ 財務支援
□ 協助宗教活動 (如：讀經、陪伴到宗教場所、協助上網參與宗教活動、拜神等) □ 其他 (請註明)________

2. 以每星期計，你平均花在主要照顧對象上的時間有多少？ 每週 __________ 小時

3. 除你以外，有否其他人同時照顧主要照顧對象？

□ 沒有 □ 其他家人或親屬 (請註明)________________________________
□ 全職家庭傭工 □ 其他受薪照顧者 (請註明)________________________________

4. 過去的 6 個月，主要照顧對象有否使用任何醫院或社區所提供的支援服務？

(如：日間護理中心及送飯服務等)

□ 沒有 □ 有 (請註明)__________________

5. 過去的 6 個月，若主要照顧對象曾使用醫院或社區所提供的支援服務的經驗，你們滿意嗎？

□ 非常滿意 □ 滿意 □ 不滿意 □ 非常不滿意 □ 不適用

丁部：**Kingston** 照顧者壓力量表

有些人表示在照顧病患家人時，會感到壓力。你在照顧您的病患家人(即乙部所提及的**主要照顧對象**)時又是否感到壓力？以下使用 5 點量表，1 代表沒有壓力，5 代表極度壓力，請對以下議題圈選出您所感到的壓力或挫折。

壓力程度大小 …		沒有壓力	有一點壓力	中度壓力	非常有壓力	極大壓力
a	您是否有被淹沒、超時工作或心力耗竭的感受？	1	2	3	4	5
b	您與配偶或親友的關係是否已經出現變化？	1	2	3	4	5
c	您是否注意到您的社交生活上有任何的變化？	1	2	3	4	5
d	與您以前日常事務(工作或義工)有任何的衝突？	1	2	3	4	5
e	您是否曾經因為照顧的責任或要求，而有被束縛或困住的感受？	1	2	3	4	5
f	您對自己的照顧能力是否曾感到信心不足？	1	2	3	4	5
g	您是否對配偶或親友的未來照顧需求感到擔心？	1	2	3	4	5
h	您與家人在照顧決策上有過衝突嗎？	1	2	3	4	5
i	在您照顧病患時，與家人的衝突有是否大於您所收到的支持？	1	2	3	4	5
j	在提供照顧上，您有出現財務上的困難嗎？	1	2	3	4	5

若閣下在過去 6 個月內………

(a) 仍然在職，可按次序繼續回答「戊部」問題。

(b) 並非在職人仕，可直接跳到「己部」回答問題。

戊部：工作地方對照顧者的支援 (只限在職人仕)

1. 在你現時工作的機構，是否有提供以下任何有關照顧患病家人方面的福利或政策？

□ 彈性工作時間　□ 額外休假日　□ 無薪假　□ 其他（請註明）____________

2. 在過去 6 個月，你有否為了照顧患病家人而曾經使用以下的福利或政策？

□ 彈性工作時間　□ 額外休假日　□ 無薪假　□ 其他（請註明）____________

3. 在過去 6 個月，你有否為了照顧患病家人申請假期而不獲批准或受到不公平的對待？

□ 沒有　□ 間中　□ 經常

4. 你有否為了照顧患病家人而作出以下工作安排 / 改變？

□ 減少工作時數　□ 改變工作模式　□ 轉換工作　□ 辭職　□ 提早退休

5. 為了照顧患病家人，你有否因而感到更大的工作壓力？

□ 沒有壓力　□ 有點壓力　□ 非常有壓力　□ 極大壓力

6. 在香港職場上，你認為因為需要照顧患病家人而遭受歧視是否普遍？

□ 非常普遍 □ 普遍 □ 不太普遍 □ 並不普遍

己部：與我們分享

1. 您有什麼關於照顧上的問題想告知我們嗎？

2. 在 **2019** 冠狀病毒疫情下，對於作為照顧者的你有否感到額外的負擔或壓力？如有，這是什麼？

3.你是否曾因為需要照顧患病家人而遭受歧視？如有，這是什麼？

Appendix 2: Caregiver Stress Interview Guide

Total 5 open-ended questions were asked during the in-depth interviews, which included

Question 1:	How did the carer responsibilities affect the participant’s daily life in different aspects?
Question 2:	Is your workplace culture caregiving friendly?
Question 3:	Any caregiving benefits, programs and policies available in your workplace?
Question 4:	Any suggestions to help make the caring process easier for you and other caregivers?
Question 5:	What makes your workplace beneficial for caregiving?

Appendix 3: Demographic characteristics of individual in-depth interview

Interviewee	**D1**	**D2**	**D3**	**D4**	**D5**	**D6**	**D7**	**D8**	**D9**	**D10**
Type of illness										
• Cancer			✓	✓	✓	✓				✓
• End Stage Organ Failure										
• Degenerative illness	✓						✓	✓	✓	
• Others		✓								
Sex										
• Male				✓	✓	✓		✓		
• Female	✓	✓	✓				✓		✓	✓
Relationship										
• Spouse				✓		✓	✓			
• Sibling										
• Adult child	✓				✓			✓	✓	✓
• Parent		✓	✓							
Social class										
• Upper Class						✓			✓	
• Upper Middle Class	✓				✓					
• Lower Middle Class			✓				✓			
• Working Class		✓						✓		
• Lower Class				✓						✓
Employment status										
• Working (FT / PT)	✓			✓	✓			✓		✓
• Non-working		✓	✓			✓	✓		✓	
Place of care										
• Hospital	✓									
• Care home		✓								✓
• Live with participant			✓	✓		✓	✓	✓	✓	
• Move to participant's home					✓					
• Live alone										

Remarks:

- **Upper:** Top level executives, celebrities, heirs & politicians
- **Upper Middle:** Highly educated, most commonly salaried, professionals & middle management
- **Lower Middle:** Semi-professionals with an average standard of living, some college education
- **Working:** Blue collar workers with low job security & high risk of poverty
- **Lower:** Rely on government transfers, occupy poorly-paid job