

MOOC 13 Caregiver Stress

Chapter 1: Formal and informal caregiving

Before starting this Chapter, please think of the answers to the following questions.

- Who are the caregivers?
- What will you encounter if you were a caregiver?
- What are the challenges or rewards in the caregiving journey?
- How could you manage the caregiving journey?
- What are the coping strategies for caregiver stress?

Do you get the answers?


You may interest to know more about caregivers. The below videos will help you to understand more about it.

After watching the videos, could you reflect on the following questions again?

- Who are the caregivers?
- What will you encounter if you were a caregiver?
- What are the challenges or rewards in the caregiving journey?
- How could you manage the caregiving journey?
- What are the coping strategies for caregiver stress?

You may realize that the caregiver role can be varied in supporting the care recipient. A caregiver may be a daughter, spouse, granddaughter, health care professional, domestic helper, friends or even a neighbor. The terms "carer" and "caregiver" are used interchangeably.

If a person suffers from chronic illness and needs constant care at home, most of the caregivers will be family member or the loved one. Taking care of a needy person is not easy which may affect your daily living, your health or even the future life plan. You may feel stressed or exhausted no matter you are trained or non-trained caregiver. Caregiving can be challenging yet rewarding. Therefore, to understand the caregiving journey and know how to support the care recipients and their caregivers are important.

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What is “Caregiving”?

In general, the term ‘caregiver’ refers to anyone who provides physical, emotional, financial, or logistical support to someone with a disabling condition or chronic illness. Zarit & Edwards (1999) stated that caregiving is “the interactions in which one family member is helping another on a regular basis with tasks that are necessary for independent living.”

Caring for loved one is associated with rewarding, including satisfaction, personal growth and personal fulfillment; however, the role of being a caregiver can be demanding physically, psychologically, socially and financially as well as role conflicts and relationship difficulties related to caregiving. The impacts of caregiving will be further discussed in Chapter 2.

Caregiving is influenced by:

1. relationship of caregivers to the care recipient
2. gender of caregivers
3. types of disease of care-recipient

The roles of caregivers

Caregiving takes many forms which includes:


- assisting in activities of daily living (ADL) and instrumental activity of daily living (IADL)
- accompanying care recipients to medical appointments
- providing financial assistance
- providing emotional support

Different types and terms of caregivers:

Do you recognize different terms related to caregiving?

Care recipient

- may have different levels of disability or suffering from chronic or acute illnesses (e.g. dementia, stroke, cancer) or may just need a little assistance with basic daily tasks (e.g. paying bills, shopping, preparing meal, attending medical appointment, taking medication, etc.).
- caregiver assists in different ways to fulfill the care recipient’s needs.

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Formal caregiver

- provides help with formal training.
- professional caregivers (e.g. doctors, nurses, therapists) who has formal professional training to provide care and get paid.
- may work in the hospitals, health care agencies or non-governmental organizations to provide assistive support. Some of them are also providing homebased services for the needy older adults.

Informal caregiver

- refers to anyone who takes care of another person in need without formal training and without paid.
- also called “the invisible patient” as they are often forgotten, and their needs are neglected.

Family caregiver

- is a kind of informal caregiver.
- refers to those who take care of their loved one at home without paid.
- It's not uncommon for a family member who are taking care of other family members may not realize that they become an informal caregiver. They just take up the caregiver roles when their family members unable to take care of themselves because of various reasons such as dementia, after an acute illness, discharged from hospital because of operation or deterioration of chronic illness.
- Different types of family caregivers:
 - Primary informal caregivers are those in the care-recipient’s network who were giving the most assistance with activities of daily living or instrumental activity of daily living to the recipient.
 - Domestic helper is also a caregiver if she is hired to work at home to take care of the disabled family members. In Hong Kong, it’s an increasing trend in hiring foreign domestic helpers to take care of older persons. In 2016, the number of households with older adults had foreign domestic helpers was about triple the figure in 2006 (Census and Statistics Department, 2018). This group of caregivers is playing an important role in supporting the families and cannot be neglected.
 - Older spousal caregiver refers to those who take care of their spousal at home without paid and formal training. As a result of the changing family structure and

population ageing, the number of older spousal caregivers is increasing which aroused the society attention. The change of political status in Hong Kong in recent year was preceded by a wave of out-migration of younger generation, resulting in putting older parents living alone in Hong Kong. There is increasing trend for older adult living with older spouse, the younger family members may immigrate to other countries, older parents may be leave unattended. The society is alerted and supporting those families.


- Long distance caregiver refers to the person who is taking care of the loved one but living in another country. Recently a lot of people are moving to other countries and leaving their older parents in Hong Kong. Some may have siblings or relatives or friends to look after their older parents, but some may be the only child that will need community support services for their older parents.

Prevalence of caregiving

There is no official statistic about caregivers in Hong Kong. However, according to the Thematic Household Survey Report No. 40 (Census and Statistics Department, 2009), which reported that out of 1,129,900 older adults, 24.8% of them needed assistance from others in their daily living. Among 280 500 older persons who needed assistance from others in their daily living, 47.6% had caregivers. Of this group of older adults with caregivers, 37.3% had their children as the major caregiver, 26.3% had their spouses and 25.6% had domestic helpers / nurses as the major caregiver.

According to the Census and Statistics Department, Hong Kong Special Administrative Region (2021):

- At least 204,200 disabled person and 248,000 people with chronic illnesses needed other person taking care of their daily living.
- Among those 204 200 persons with disabilities, 28.7% were taken care of by their children/son-in-law/daughter-in-law, 28.2% were their domestic helpers, 20.7% were their spouses and 15.0% were their parents.
- Among those 248 000 persons with chronic diseases, 31.9% were taken care of by their children/son-in law/daughter-in-law. 28.9% were their spouses, 24.5% were their domestic helpers and 7.9% were their parents.
- The median usual hours of caring services provided by the carer per week to those persons with disabilities and those persons with chronic diseases were 42 hours and 35 hours.

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The Hong Kong Council of Social Services (2021) conducted a caregiver survey with 719 caregivers. Findings:

- more than 70% of the interviewed caregivers were female.
- about half (52.2%) were 55 years old or above.
- more than 30% (36.9%) were 35 to 54 years old and about 10% (10.9%) were aged 34 or below.
- about half of the caregivers in these two age groups, aged 34 or younger, and those aged 35 to 54, were employed caregivers. They were feeling great stress because they had to take care of their needy family member while working a full time or part time job.
- caregivers spend more time in caring than those in foreign countries:
 - spend two to three hours less on leisure and sleep than the average Hong Kong people.
 - the weekly care hours of working caregivers are higher than the median working hours of 44 hours per week for Hong Kong people, and the number of non-working caregivers is as high as 80 hours per week, which is almost twice the working hours in Hong Kong.

According to Census and Statistics Department (2023) report “2021 Population Census Thematic Report: Older Persons”, in 2021, the number of domestic households with elderly members:

- in 2011, the number of such households grew by 52.6% from 668,621 to 1,020,356.
- its share among all domestic households rose from 28.2% to 38.2% during the same period.
- there was a significant increase (in both number and share) in domestic households with elderly members.

Among all persons aged 60 and over living in domestic households in 2021, 16.6% (330,164 persons) required long-term care. The proportion of persons requiring long-term care:

- aged 60 to 69, 18.7%,
- aged 70 to 79, 27.9%
- 80 and over, 53.4%

The proportion of older women requiring long-term care was 19.8%, higher than the corresponding proportion for elderly men (13.1%). It is worth noting that female outnumbered male for all age groups among persons aged 60 and over with long-term care needs.


Challenges in caregiving

- Increasing population ageing, increasing demand of caregiving.
- Short stay in hospital and age-related frailty, informal caregivers are playing the key roles to deliver long-term care at home.
- Female and male caregivers are facing different challenges.
 - Female caregivers being the predominate caregiver having a competing role play.
 - Refer to the previous video, Ling is playing different roles and is struggling in the caregiving role and as a working mom. She has her job duty in workplace and is working as a care coordinator, a daughter, a mother who is feeling frustrated and exhausted.
 - Male caregivers are increasingly taking up their role in caregiving.
 - Social norm - caregiving role is usually perceived as feminized.
 - Hidden caregiver.
 - Uncomfortable with hands-on personal care.
 - Less open up to others they feel stressed or overwhelmed by caregiving responsibilities.

Challenges for formal caregivers

- Unsatisfactory working conditions
- Workforce shortage with high turnover rate
- Overwhelming workload
- Low job satisfaction
- High physical and emotional demand
- Challenging care recipients
- Insufficiency governmental funding
- Lack of training and resources

Li & Song, 2019


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Challenges for informal caregivers

- Lack of training and knowledge. Limited carer support services and long waiting list.
- Shortage of manpower and space while family carers are often challenged by an overwhelming care burden.
- Caregivers has insufficient information about the community care services.
- Caregivers are the vulnerable group who are at-risk for multiple and serious physical and mental health conditions.
- Caregivers have multiple, varied, and serious unmet needs which is not being addressed.
- Family caregivers are experiencing significant burden.

Li & Song, 2019


Let's move on to Chapter 2 to know more about carer stress, caregiver burden and burnout.

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