

**The Chinese University of Hong Kong
The Nethersole School of Nursing
CADENZA Training Programme**

**CTP 003: Chronic Disease Management and
End-of-life Care**

**Web-based Course for
Professional Social and Health Care Workers**

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Chapter 7

Informal Care-giving for Older People with Chronic Diseases



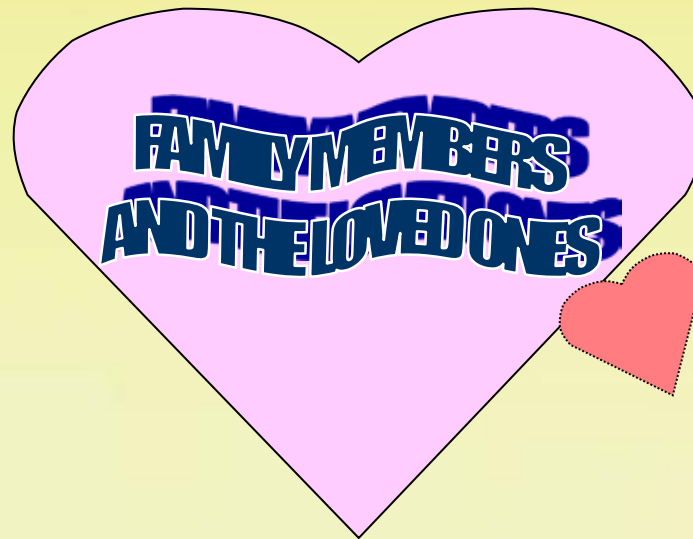
Lecture Outline

- Definitions of "Carer" and "Caregiving"
- Effects of long term caring for older people with chronic diseases
- Reasons of stress for long term informal caregivers
- Symptoms of caregiver stress
- Assessment tools for caregiver stress level
- Management of caregiver stress

Introduction

- There is an old Chinese saying "瞥泔鸚鑼砵臄篡"
- Although the perception is very negative, to a certain extent it reflects the truth that chronic illnesses sometimes make people feel annoyed.

- If a person suffers from chronic illness and needs constant care at home, the majority of these informal caregivers will be:



Who is a "Carer"?

- A carer is someone who provides voluntarily care and support to someone unable to manage without such support. A carer may be a spouse, child, relative, friend or neighbour.
- However, a "care-worker" or "care assistant" is someone who receives payment for looking after someone.

Who is a "Caregiver"

- A caregiver is a person who cares for someone in need, such as an ageing parent, infirm spouse or friend.
- Provides care and also resources to meet the physical and daily needs of the one cared for.

(The University of Texas at Austin, 2008).

- The terms "carer" and "caregiver" are used alternately.
- They refer to the person who provides care to the dependent.

(Oyebode, 2003)

- Sometimes a carer has no choice but to be a carer if the object of care happens to be a family member.
- ✿ However, that person may **not** think of themselves as a "carer", they simply look after their family member as a normal responsibility. Thus, they may not foresee the effects long term caring may have on them.

What is "Caregiving"?

- Zarit & Edwards (1999) in Oyebode (2003, p.46) 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.”

(Zarit & Edwards, 1999)

- In a study conducted in 1996 to examine the long term care needs, patterns and impact of the elderly in Hong Kong, it was found that over 88% of older people were living with their spouse. Living with a son was the second most common arrangement.

(Ngan, et al., 1996)

What is Informal Caregiving?

- According to the Thematic Household Survey Report No. 40 ,2009:
- older people are considered to have informal care if they receive care from household members, friends, neighbours or domestic helpers.

(Census and Statistics Department, 2009)

- The level of informal care received by older people is classified into five levels.
- Care is indicated by the level of assistance from others in their daily living.
- To read the report, please visit:
- <http://www.statistics.gov.hk/pub/B11302402009XXXXB0100.pdf>

(Census and Statistics Department, 2009)

Impact on Long-term Caring

Long term caring means

- devoting a great deal of time
- expending energy
- strenuous effort
- making numerous sacrifices
- change of life style
- female caregiver has to juggle a number of roles: wife, mother, daughter, caregiver, daughter-in-law, and worker

- Taking on a long-term caring role may affect the carer's physical, psychosocial and spiritual wellbeing.
- Constant stress may result in “burnout”.

What is "Carer Stress"?

- "Carer stress" is defined as "the **emotional strain** of caregiving and results from the unique pressures and demands placed on caregivers."

<http://www.utexas.edu/hr/current/services/informational/caregiver.html>

(The University of Texas at Austin, 2008).

Caregiver's Voice

I need to care for my one year old son as well as care for my bedridden dad who had a stroke a few months ago and 24 hours in a day is definitely not enough for me

I am 69 years old, I have great difficulty chasing after my husband, who is severely demented.

I don't want to quit my job - I like it - but how can I find time to care for my dad who is now homebound with multiple arthritic pain?

- There are lots of true stories that reflect caregivers' struggles to balance caregiving with other responsibilities.
- They may struggle alone without knowing how to get help or relief.
- Although friends and relatives may sometimes help, **caregivers still do most of the caregiving.**

Facts about Caregivers

- In America, the responsibilities of caregivers include:

help with medication

transportation

grocery shopping

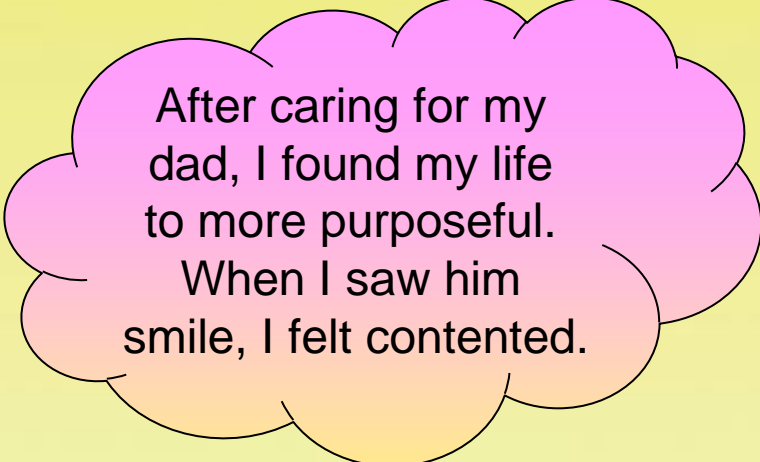
household chores

activity of daily living

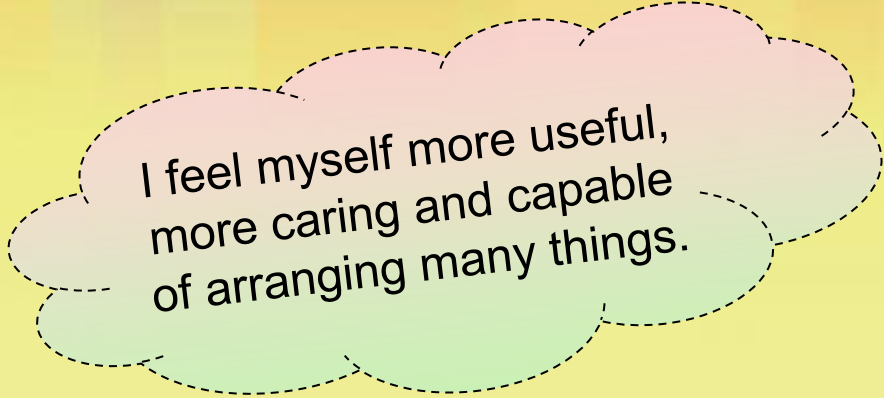
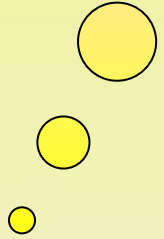
- They have less time for:
 - family members,
 - vacations,
 - hobbies
 - other activities.

However, NOT all long term
caregivers suffer
carer stress

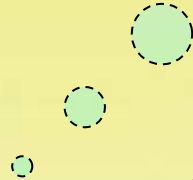
Caregivers' Voice



After caring for my dad, I found my life to more purposeful. When I saw him smile, I felt contented.



I feel myself more useful, more caring and capable of arranging many things.



I can fulfill my practice of filial piety and it's my responsibility to do so.

- Long-term caring implies 24 hours a day without a regular day off or annual leave.
- There are numerous implications for caregivers especially when caring for old people. It is important to know whether the caregivers can continue in this role for long and therefore early detection of caregiver stress is important.

- Different caregivers may experience different levels and types of stress in caring for older family members.
- A study in the UK examined the activities and perceptions of 41 spouses and adult daughters seeking psychological and social intervention when caring for their frail spouse or parent. The results were interesting...

- The main stress of the spouse arose from:
 - Ø the identification of their marital relationship
 - Ø hands-on care
 - Ø their own physical abilities
- Whereas the daughters' stress was less attributable to direct care. The main source of stress arose from:
 - Ø the identification of responsibilities
 - Ø the competing demands outside the caregiving relationship

(Rankin, 1990)

Caregiver Stress

- Different caregivers may have different concerns in their long term caring relationship. However, they should realise when too much stress is placed upon them and seek help as soon as possible.

Common Signs of Caregiver Stress

- Feeling overwhelmed
 - general anxiety
- Easily irritated, angered or saddened
- Sleeping problems
 - sleeping too much or too little
- Feeling tired or unenergetic most of the time
- Loss of interest in activities one used to enjoy

- Change in eating habits
 - weight loss or gain
- Frequent headache, epigastric discomfort or other physical symptoms
- Role overload
 - difficulty in meeting other demands
- Financial stressors
- Absenteeism
 - miss routine work to spare extra time in the caring role

(The University of Texas at Austin, 2008).

<http://www.utexas.edu/hr/current/services/informational/caregiver.html>

Stress Assessment Tools

- There are different kinds of stress assessment tools:
 - Zarit Burden Interview
 - Caregiving Burden Scale
 - Caregiving Hassles Scale
 - Behavioural Assessment Scale of Later Life

Examples of Caregiver Self-assessment Tools

- Please go to the website and fill out the 20 multiple choice questions to determine whether you have stress, or what level of stress you may experience if you were to be a caregiver.

<http://www.caregiverstress.com/stress-management/stress-symptoms/caregiver-stressmeter/>

Another example of a caregiver self-assessment tool (in Chinese)

<http://www.familycare.org.tw/index.php/navigations>

Zarit Burden Interview (ZBI)

- The most common tool is the "Zarit Burden Interview".
- It is a 22-item self-report scale which measures subjective carer burden.
- To view the assessment tool, please click the following link:

<http://www.rgpc.ca/best/GiiC%20Resources/GiiC/pdfs/3%20Caregiver%20Support%20-%20The%20Zarit%20Burden%20Interview.pdf>

For the research, please click:

<http://www.mapi-trust.org/services/questionnairelicensing/catalog-questionnaires/97-zbi>

Zarit Burden Interview

- Instructions for caregiver:
 1. circle the word that best describes the situation
 2. there are no right or wrong answers
- Scoring instructions:
 1. add up the scores for the 22 questions
 2. the total score ranges from 0 to 88
 3. a high score correlates with higher level of burden

(Parks & Novielli, 2000).

- Chan TSF et al. (2005) conducted a study to validate the Chinese version of the Zarit Burden Interview.
- The result showed the Chinese version of the ZBI to be a reliable and valid instrument in assessing the subjective burden of caregivers to patients with dementia in the Chinese population.

(Chan et al, 2005)

- Caregivers must take care of themselves in order to take care of others.
- There are several tips to help relieve stress.

Management of Stress for Caregivers

- Nolan et al. (1996) cited in Oyebode (2003) the **nine** most popular strategies that caregivers found most helpful in relieving stress. The summary is as follows:
 - realise the person they care for is not to blame for his/her position
 - take life "one day at a time"
 - keep a little free time for oneself
 - find out as much as you can about the problem

- there is always someone worse off than themselves
- no one is to blame for things
- keep one step ahead of things, plan in advance
- get as much help as possible from professionals and service providers
- talk to someone trustworthy

(Nolan, et al ,1996)

Tips for Relieving Carer Stress

- Eat healthy
 - well-balanced diet, rich in fruits and vegetables, grains and protein; avoid caffeine and alcohol; no overeating
- Sleep well
 - take short naps throughout the day
- Regular exercise
 - learn stress management exercises, such as yoga
 - set aside 20 min. per day for exercise

- Meditation
 - when things are moving too fast, sit still and breathe deeply to quieten the mind
- Prioritise and establish a daily routine
 - take one day at a time and don't rush things
- Seek out caregiver resources or support groups
 - seek community resources

- Get in touch with friends and relatives
 - let friends and relatives know the progress of both caregiver and the one needing care, thus others will know when to help out
- Indulge
 - go out for dinner, take a facial treatment or buy a new clothes - do not feel guilty about occasional treats

- Regular physical check ups, especially if health appears to deteriorate
- Take a break
 - take time out when too exhausted and find someone to act as relief
- Religious support
 - attend religious activities and pray

(Caregiverstress.com , 2008).

- “Accept” and “let go” are keys to releasing stress
- A serenity prayer helps caregivers release stress and develop a positive attitude toward stress:

“God grant me the serenity to accept the things I cannot change, courage to change the things I can and wisdom to know the difference.” *(Niebuhr)*

<http://www.cptryon.org/prayer/special/serenity.html>

Survival Strategies

Obstacles to Overcome

There are some obstacles to overcome that hinder one from being an effective caregiver. They are:

- unrealistic expectations
- doubts and fears due to lack of knowledge, time, and strength to carry out the responsibilities
- the role of caregivers is not planned
- physical and emotional fatigue

(Pipenbrink (Ed.),2002)

- discouragement and depression, especially for someone looking forward to other enjoyable living after retirement
- anger and bitterness due to lack of support from family and society

(Pipenbrink (Ed.),2002)

Survival Strategies for Caregivers

- Caring for older people with chronic disease is long-term, therefore caregivers must have strategies to prevent burnout.
- Don't do it alone; keep good friendships with people or look to God for support.
- Know what you need and keep digging for resources.
- Accept help from your family; hold a family meeting to talk about the role.
- Join a carer support group.

(Pipenbrink (Ed.),2002)

- Seek your strengths.
- Reallocate your job to fit the caregiver role.
- Get respect for a while to.
- Don't think unrealistically.
- Energise yourself by finding out what makes you refresh life, then practice regularly and consistently.
- Find strength in your faith and calling, find spiritual strength.

(Pipenbrink (Ed.),2002)

Carer Support Service in Hong Kong

- Aim:
 - To facilitate and support carers in taking care of older people in the community.
 - Most community support service units, including District Elderly Community Centre (DECC), Neighbourhood Elderly Centre (NEC), Day Care Centre (D/Es) and Day Care Units (DCUs) for the Elderly, Integrated Home Care Services (IHCS) and Enhanced Home and Community Care Services (EHCCS) provide various kinds of carer support services in Hong Kong.

Carer Support Service in Hong Kong

- Target Groups
 - Informal carers such as family members, relatives and friends who take care of older people in the community.
 - General public.
- Fees and Charges
 - Annual membership fee and fees for individual programmes.

Carer Support Service in Hong Kong

- **Scope of Service**

- skill-training and educational programmes
- self-help and mutual support groups
- resource corner
- counselling and referral services
- information giving and supply of reference materials relating to the care of older people
- demonstration/loan of rehabilitation-aid equipment
- social and recreational activities

Social Welfare Department (2008a).

Residential Respite Service

- Another service for relieving carer stress in Hong Kong.
- Provides temporary or short-term residential care service for older people.
- It serves the objective of providing temporary relief to the main caregivers of older people.
- There are 11 care-and-attention places designated for respite service in subvented residential care homes for the elderly.
- For more information, please visit the Social Welfare Department website below:
- http://www.swd.gov.hk/en/index/site_pubsvc/page_elderly/sub_csselderly/id_carersuppo/

Social Welfare Department (2008b)

Carer Support in Other Countries

- In the U.S., **the National Family Caregiver Support Program (NFCSP)** is a federally funded programme through the Older Americans Act. It provides services to assist family caregivers. Each state offers different amounts and types of services, e.g.,
 - help in accessing support services
 - individual counselling
 - support groups
 - caregiver training
 - respite care
 - limited supplementary services

- **The Utah Coalition for Caregiver Support**, established in the state of Utah in 2003, is a group of professionals with a common interest in issues relating to caregiving and older people.
- It acts as advocate for caregivers, provides information about caring, etc.
- More information on Utah Coalition for Caregiver Support, please visit: <http://www.caregivers.utah.gov/>

- In Australia, **The Home and Community Care Act 1985** includes caregivers as recipients of various funded services for the frail elderly and for younger people with disabilities.
- The Home and Community Care (HACC) services provided through local government and non-government organisations in Victoria include:
 - general home help, personal care, home maintenance and modifications, meals, community nursing, transport and respite

(Schofield, et al (Eds.), 1998)

Conclusion

- The impact of long term caring for chronic diseases may be serious and stressful.
- It affects the caregivers's physical, emotional, social and financial states.
- Family and friends' support is important, but at the same time, social and government support also play an important role.

- In order to minimise caregiver stress and help older people succeed in "ageing in place", healthcare professionals and policy makers should recognise the needs of both older people with chronic diseases *and* caregivers, so as to plan strategies which optimise quality of life for all concerned.

- Government policy should be based on:
 - designating caregivers a specific and independent client status alongside the care-recipient
 - taking a preventive approach by providing information and education to caregivers

- strong community home care services to support caregivers in case of emergency
- interdisciplinary effort offering well-coordinated, flexible services depending on the needs of the older people and the caregivers
- regular review

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