

# MOOC 13 Caregiver Stress

## Chapter 2: Caregiver Burden, stress and burnout

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.

Caregiver stress is caused by the ongoing emotional and physical strain of caregiving. Stressed caregivers may experience fatigue, anxiety and depression.


Caregiver burden is the level of multifaceted strain perceived by the caregiver who provide long term care for their chronically ill, disabled, or older family member (Kazemi et al., 2021; Liu et al., 2020). It is a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience.

Caregiver burnout is a state of physical, emotional and mental exhaustion. Burnout can happen when you are unable to tolerate or manage the caregiving stress and can't get help or without support. You may also feel guilty because of your inability to care for your loved one.

### Impacts of caregiving

- Physical health e.g. new or worsening health problems
- Mental and emotional health e.g. anxiety, depression, irritable
- Isolation and loneliness
- Relationship difficulty e.g. conflicts with the family members
- Financial problems e.g. medical expenses, home modifications, transportation
- Employment impacts e.g. quit job, retired early, take up more job

A local study in dementia caregiving revealed that 73.7% of working caregivers were exposed to high levels of caregiver stress, 46.2% had symptoms of depression and 38.6% experienced family conflict (The HSBC Life (International) Limited, the Sau Po Centre on Ageing at The University of Hong Kong & the Women's Foundation, 2020).

 The logo for Jockey Club e-Tools for Elder Care, featuring a stylized 'Cadenza' with a musical note and the Chinese text '賽馬會流金箱 護老有道'.	File	Handout – Caregiver Stress - Chapter 2
	Copyright	© 2023 Jockey Club CADENZA e-Tools for Elder Care. All Rights Reserved.
	Page	1

The care burden of dementia family caregivers is much greater than that of other family caregivers. They are more likely to experience:

- high level of care involvement
- higher level of stress and low level of self-efficacy
- higher level of social, physical and emotional strain
- poorer mental health and physical health

### **Male caregivers vs female caregivers**

Female caregivers:


- tended to report higher levels of depression, anxiety, and general psychiatric symptomology, and lower level of life satisfaction than men caregivers
- spent more time on caregiving than men in terms of the number of caregiving tasks performed
- tended to be exposed to greater caregiving demands than men, especially in terms of time spent on caregiving, and the performance of hands-on, day-to-day caregiving activities
- experienced higher burden than men

### **Caregivers at high risk of caregiving burden**

- long and intensive caregiving tasks
- history of domestic violence
- behavioral disturbance of care recipients
- lack of recognition and support from carers' immediate circle
- caregiving for multiple dependents with disabilities
- having suicidal thoughts and/or murder-suicide thoughts

(The Hong Kong Polytechnic University Consulting Team,2022)

During the COVID-19 pandemic, the mental health of carers was affected tremendously due to the partial disruption of community services and social isolation measures.

	File	Handout – Caregiver Stress - Chapter 2
	Copyright	© 2023 Jockey Club CADENZA e-Tools for Elder Care. All Rights Reserved.
	Page	2

### Significant factors associated with a higher care burden

- being a spousal carer
- female
- lower income level
- having a medical diagnosis of emotional issues
- cancer, diabetes, or poorer perceived health status

(The Hong Kong Polytechnic University Consulting Team, 2022)

Warning signs	
Caregiver stress	Caregiver burnout
<ul style="list-style-type: none"> <li>• Anxiety, depression, irritability</li> <li>• Feeling tired and run down</li> <li>• Difficulty sleeping</li> <li>• Overreacting to minor nuisances</li> <li>• New or worsening health problems</li> <li>• Trouble concentrating</li> <li>• Feeling increasingly resentful</li> <li>• Drinking, smoking, or eating more</li> <li>• Neglecting responsibilities</li> <li>• Cutting back on leisure activities</li> <li>• Avoiding social interaction</li> </ul>	<ul style="list-style-type: none"> <li>• Have much less energy</li> <li>• Tend to catch every cold or flu</li> <li>• Constantly exhausted, even after sleeping or taking a break</li> <li>• Neglect your own needs, either because you're too busy or you don't care anymore</li> <li>• Life revolves around caregiving, but it gives you little satisfaction</li> <li>• Have trouble relaxing, even when help is available</li> <li>• Increasingly impatient and irritable with the care recipient</li> <li>• Helpless and hopeless</li> </ul>

Source: Leeza's Care Connection

<https://leezascareconnection.org/resources/im-new-caregiving-now-what-2-2/preventing-caregiver-burnout>

## Caregiver Assessment

### Why should we assess family caregivers?

- To determine if the caregiver is able/willing to assume care responsibilities and the care recipient is willing to accept care.
- To identify care needs and caregiving issues.
- To create a personalized care plan to meet specific and changing needs.
- To improve caregivers' understanding of their role and what they need to know to carry out tasks.
- To empower family caregivers to make informed decisions of care options and link caregivers with appropriate community services in order to improve outcomes for caregivers and care recipients.

### Who should conduct the family caregiver assessment?


Preferably, both caregiver and care recipient are assessed by the same assessor together or separately. Coordinated assessment by multi-disciplinary professionals can also be adopted.

A range of professionals can conduct a caregiver assessment including:

- Social Workers
- Care Managers
- Nurses
- Physicians
- Rehabilitation Professionals i.e., Physiotherapists, Occupational Therapists, Speech Therapists

### Who should be assessed?

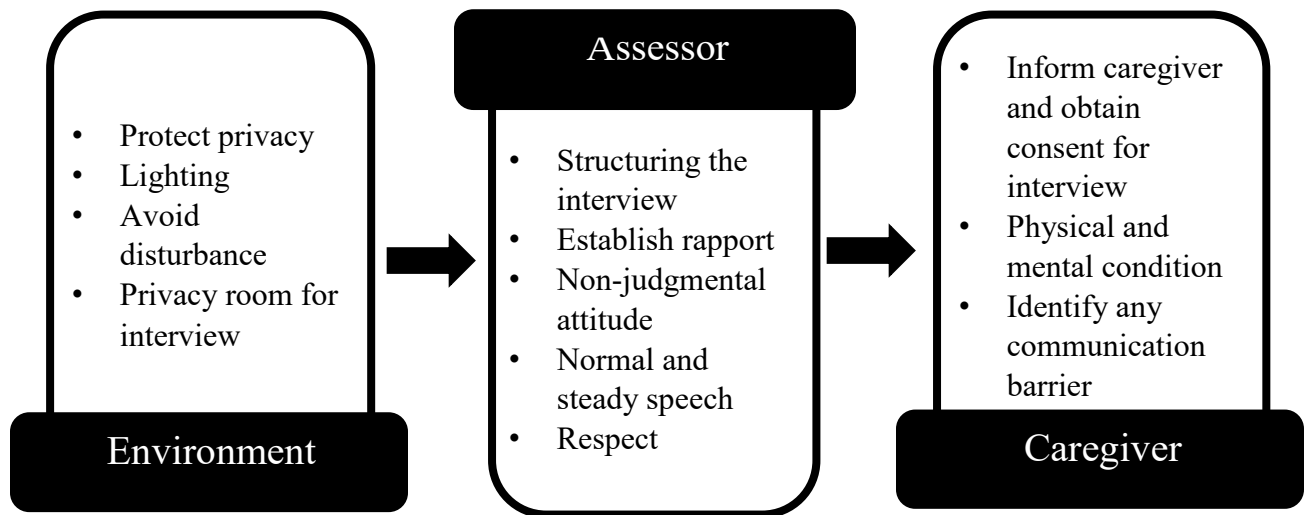
- Those who are involved in caregiving should be assessed.
- Identify those involved in caregiving but do not know they are caregivers.
- Be aware that when multiple family members are involved in caregiving, conflict resolution may be necessary to sort out roles and feelings.

	File	Handout – Caregiver Stress - Chapter 2
	Copyright	© 2023 Jockey Club CADENZA e-Tools for Elder Care. All Rights Reserved.
	Page	4

## Assessment Process

Assessment can be conducted by face-to-face, telephone, self-administered, electronic, structured interview. Periodic reassessment is strongly recommended to identify changes in care situation. It can also be done on a need basis.

Preparation:



### Assessor should:

- Identify who is the primary caregiver and who are involved in caregiving.
- Understand the purpose of assessment.
- Choose appropriate assessment tools and familiar with them.
- Use active listening.
- Non-judgmental attitude.
- Adopt professional communication skills to engage with caregivers.
- Be sensitive to differences in framing questions around culture, religion, age, etc.
- Empathize with the caregiver.
- Dealing with emotional content.
- Structure the interview guide and recognize what you know, what you do not and when to hand off.
- Disseminate appropriate and clear information and refer to suitable services as needed.

## Domains of Assessment

1. Background on the caregiver and the caregiving situation including sociodemographic information of caregivers, household composition and income, family relationship but not limited.
2. Caregiver's perception of health and functional status of the care recipient.
3. Caregiver's values and preferences with respect to everyday living and care provision.
4. Health and well-being of the caregiver.
5. Consequences of caregiving on the caregiver (challenges and benefits).
6. Care-provision requirements (skills, abilities, knowledge).
7. Resources to support the caregiver. Utilizations of community support services.

## Assessment tools

A well-structured professional assessment is important to collect necessary information to identify caregivers' needs and create a tailor-made care plan that can improve outcomes for caregivers and care recipients. Standardized assessment tools are used to obtain information. Measures must have good psychometric properties. There are a few examples such as Zarit Burden Interview, Caregiver Strain Index, Caregivers Burden Inventory etc.

Zarit Burden Interview (ZBI) 沙氏負荷量表
<ul style="list-style-type: none"><li>• well-known measure of caregiving burden in caregivers of patients with dementia.</li><li>• multidimensional aspects including physical, emotional, financial and social burden and the relation with the care receiver.</li><li>• considered as the first burden scale to evaluate the subjective impact of caregiving.</li><li>• was primarily designed to be used in research and program evaluation purposes.</li><li>• consists of 29 items but was shortened to 22 items, rating in each item by a 4-point Likert scale (never to nearly always; 1-4).</li><li>• a higher score indicates a higher burden.</li></ul>

<p>Caregiver Strain Index 照顧者負荷指數</p> <ul style="list-style-type: none"> <li>• multi-dimensional burden scale.</li> <li>• consists of 13 items such as feeling of inconvenience, confinement, adjustment, competing demand, upsetting behaviors, needing the care receivers to be different, feeling overwhelmed sleep disturbance, and physical and financial strain.</li> <li>• in Yes/No format (Yes=1 and No=0) &amp; sum up the scores.</li> <li>• score of 7 or greater indicating a high level of stress.</li> </ul>
---

<p>Caregivers Burden Inventory 照顧者負擔量表</p> <ul style="list-style-type: none"> <li>• multi-dimensional burden scale.</li> <li>• was designed specifically to assess caregivers of cognitively impaired older people.</li> <li>• Consists of 24 items in 4-point Likert scale ranging from never (0) to always (4)</li> <li>• 24 items divide into 5 factor subscales (physical burden, time dependence burden, developmental burden, social burden and emotional burden).</li> <li>• a higher score indicates a higher burden.</li> </ul>
--

<p>Assess caregiver distress related to behavioral and psychological symptoms</p> <ul style="list-style-type: none"> <li>• Neuropsychiatric Inventory Questionnaire (NPI-Q)</li> <li>• Behavioral Pathology in Alzheimer's Disease Rating Scale (BEHAVE-AD)</li> </ul>
--

### Assessments for psychiatric morbidity

- Global rating of mental health
- Center for Epidemiological Studies the–Depression Scale (CES-D)
- Geriatric Depression Scale
- General Health Questionnaire
- State Trait Anxiety Inventory (STAI)
- Structured clinical Interview for DSM IV

### Assessments for physical morbidity

- Global physical health ratings
- Physical symptoms index
- Objective physiological parameters, e.g. blood pressure and heart rate
- Health service utilizations, such as, physician visits, aggregate use of health services, and drug utilization
- Health related behaviours, including alcohol consumption, smoking behavior, sleep, and eating behavior/nutrition

### Assessments for care recipients

- Background and medical history
- ADL
- IADL
- Health and mental status

### Indicators for positive outcomes

- Uplifts
- Caregiving satisfaction
- Rewards
- Gratifications
- Finding meaning through caregiving
- Benefits
- Positive affect
- Life satisfaction

### Positive Aspects of Caregiving (PAC)

- assess the perception of benefits within the caregiving context, such as feeling useful, feeling appreciated, and finding meaning.
- nine-item scale, on a five-point Likert scale (agree/disagree).
- scores ranged from 9 to 45, with higher scores indicating more positive caregiving appraisals.



Caregivers undergo significant stress or burden in the caring process. If we did not handle stress properly, caregivers may experience burnout and do harmful actions which lead to elder abuse.

## Elder Abuse

Case story - Elder Abuse case story

The 45-year-old son is the main caregiver who is living with his 75-year-old frail mother. He confessed to repeatedly slapping his mother because she constantly yelling at night for toileting. Sometimes the two got into arguments about the minor family chores. He stressed “I just lost my temper at the way my mother talked to me!”

In your daily practice, did you notice any suspected abused case?

How could you help?


Elder abuse is happening worldwide and is a public health issue (WHO, 2022). Elder abuse is a complex issue. Older adults are reluctant to report elder abuse because most of the cases are abused by their family members. Older adults are vulnerable group who are living with disability and depending on their family members or caregivers’ assistance in daily livings. The abusers may be the health care workers in the residential care homes. Or they may even have close relationship with the older adults.

## Definition of Elder Abuse

Elder abuse is a single or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust, which causes harm or distress to an older person. This type of violence constitutes a violation of human rights and includes physical, sexual, psychological and emotional abuse; financial and material abuse; abandonment; neglect; and serious loss of dignity and respect (WHO, 2022).

In Hong Kong, elder abuse refers to the commission or omission of any act that endangers the welfare or safety of an elderly person. Usually, the elderly person being abused and abuser are known to each other, or abusers are responsible for the care of the elderly person being abused (SWD, 2022).

We believe that everybody has the right to survival, freedom and personal safety, and the right to obtain basic provisions for living. No one, including elderly persons, should be treated with cruelty, inhumanity or insult.

	File	Handout – Caregiver Stress - Chapter 2
	Copyright	© 2023 Jockey Club CADENZA e-Tools for Elder Care. All Rights Reserved.
	Page	9

## Prevalence

Social Welfare Department (2022) has periodical report on the statistic of abuse cases. The ‘Procedural Guidelines for Handling Elder Abuse Cases’ was reviewed and updated in 2021. Based on the information collected by the Central Information System on Elder Abuse Cases, the statistics on newly reported elder abuse cases for the period from January to September 2022 are as follows:

### Type of Abuse and Incident Being or Not Reported to Police

Type of Abuse	Reported to Police		Not Reported to Police		Total	
	No. of Cases	%	No. of Cases	%	No. of Cases	%
Physical abuse	144	72.4%	43	75.4%	187	73%
Psychological abuse	23	11.6%	7	12.3%	30	11.7%
Neglect	0	0.0%	0	0.0%	0	0.0%
Financial abuse	10	5.0%	0	0.0%	10	3.9%
Abandonment	0	0.0%	0	0.0%	0	0.0%
Sexual abuse	3	1.5%	1	1.8%	4	1.6%
Others	0	0.0%	0	0.0%	0	0.0%
Multiple abuse	19	9.5%	6	10.5%	25	9.8%
Total	199	100.0%	57	100.0%	256	100.0%

Resource: Social Welfare Department, (2022). Services for Prevention and Handling of Elder Abuse.

### Abuser's Relationship with Elderly Person Being Abused and Incident Being or Not Reported to Police

Abuser's relationship with Elderly Person Being Abused	Reported to Police		Not Reported to Police		Total	
	No. of Cases	%	No. of Cases	%	No. of Cases	%
Son	30	15.1%	7	12.3%	37	14.5%
Daughter	6	3.0%	4	7.0%	10	3.9%
Son-in-law	1	0.5%	0	0.0%	1	0.4%
Daughter-in-law	3	1.5%	1	1.8%	4	1.6%
Spouse/intimate partner	144	72.4%	44	77.2%	188	73.4%
Grandchildren	1	0.5%	0	0.0%	1	0.4%
Relative	1	0.5%	0	0.0%	1	0.4%
Friend/neighbour	2	1.0%	1	1.8%	3	1.2%
Not relative but living together	1	0.5%	0	0.0%	1	0.4%
Domestic helper	4	2.0%	0	0.0%	4	1.6%
Staff of the agency providing services for the elderly person	4	2.0%	0	0.0%	4	1.6%
Others	2	1.0%	0	0.0%	2	0.8%
Total	199	100.0%	57	100.0%	256	100.0%

Resource: Social Welfare Department, (2022). Services for Prevention and Handling of Elder Abuse.

#### Points to note:

- The top 3 elder abuses are physical abuse, multiple abuse and psychological abuse.
- Over 22% cases were not reported to police. Perhaps it's only the tip of iceberg.
- Most of the abused cases were female.
- Most abusers were the victims' spouse and intimate partners.
- We should report any suspected abused cases in order to stop elder abuse and protect those being abused.

For latest data, refer to [Social Welfare Department - Services for Prevention and Handling of Elder Abuse \(swd.gov.hk\)](http://www.swd.gov.hk).

**Types of abuse (SWD, 2022):**

1. Physical
2. Sexual
3. Psychological and emotional abuse
4. Financial and material abuse
5. Abandonment
6. Neglect
7. Serious loss of dignity and respect (WHO, 2022)

**Identify those at risk**

**Older adults who are/have:**

- functional dependence/disability
- poor physical health
- cognitive impairment
- poor mental health
- low income
- living in nursing homes

During the COVID-19 pandemic, the rate of abuse of older adults had increased. Caregiver burnout may trigger elder abuse.

Lower risk of elder abuse: for those who are living alone or have social support would have lower risk of elder abuse.

**Risks of becoming a perpetrator of abuse**

- mental illness
- substance abuse
- financial dependency of the abuser on the victim

## Prevention and Intervention

We should aim to arouse the awareness of professionals, older adults and public on the problem of elder abuse, to prevent the occurrence of abusive incident, and to encourage victims and abusers to seek assistance as early as possible so as to remedy the situations.

### Watch for signs of abuse:

- Seems depressed, confused, or withdrawn
- Isolated from friends and family
- Has unexplained bruises, burns, injury or scars
- Appears dirty, underfed, dehydrated, over-or undermedicated, or not receiving needed care for medical problems
- Has pressure injuries or other preventable conditions
- Recent changes in banking or spending patterns

### What should I do if I suspected elder abuse case?

If you suspect that the older adults around you are being abused, you can take the initiative to care about and listen to their needs, and encourage them to seek help and consultation from trusted relatives, friends and professionals, so that the abused person can obtain the most suitable services.


Hotline of Social Organizations	Tel. No.
Social Welfare Department (Hotline for inquiry)	2343 2255
The Haven of Hope Christian Service (Elderly Protection Centre) (Hong Kong and Kowloon East)	2915 8888
Christian Family Service Centre	2787 6865
Caritas Family Crisis Support Centre	18288
CEASE Crisis Centre 24-hour Hotline	18281

Resource: Elderly Health Service, Department of Health

Please refer to the 'Procedural Guidelines for Handling Elder Abuse Cases (Revised 2021)' for handling of elder abuse.

- Procedural Guidelines for Handling Elder Abuse Cases (Revised 2021) (swd.gov.hk)
- Chapter 11 Appendices I - III: Reporting Guidelines, Flowchart and Data Input Form for the 'Central Information System on Elder Abuse Case'

[https://www.swd.gov.hk/en/index/site\\_pubsvc/page\\_elderly/sub\\_csselderly/id\\_serabuseelder/](https://www.swd.gov.hk/en/index/site_pubsvc/page_elderly/sub_csselderly/id_serabuseelder/)

 <p>Jockey Club <b>Cadenza</b> e-Tools for Elder Care 賽馬會流金箱護老有道</p>	File	Handout – Caregiver Stress - Chapter 2
	Copyright	© 2023 Jockey Club CADENZA e-Tools for Elder Care. All Rights Reserved.
	Page	14

## References

- Elderly Health Services, Department of Health, HKSAR, (2022). *Elder Abuse*. [https://www.elderly.gov.hk/english/carers\\_corner/caring\\_skills/prevention\\_of\\_elder\\_abuse.html](https://www.elderly.gov.hk/english/carers_corner/caring_skills/prevention_of_elder_abuse.html)
- Family Caregiver Alliance. (2023). *Caregivers Count Too! – Section 3: The Nuts & Bolts of Caregiver Assessment*. <https://www.caregiver.org/resource/caregivers-count-too-section-3-nuts-bolts-caregiver-assessment/>
- Garand, L., Dew, M. A., Eazor, L. R., DeKosky, S. T., & Reynolds, C. F., (2005). Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *International journal of geriatric psychiatry (3<sup>rd</sup> ed.)*, 20(6), 512–522. <https://doi.org/10.1002/gps.1318>
- Ho, S. C., Chan, A. C. M., Lau, J. T. F. & Woo, J. (2007). A study of informal caregivers and the association of caregiving status with health and quality of life. *Hong Kong Med J*, 13(5), 4-7.
- Kazemi, A., Azimian, J., Mafi, M. et al. (2021). Caregiver burden and coping strategies in caregivers of older patients with stroke. *BMC Psychol*, 9, 51. <https://doi.org/10.1186/s40359-021-00556-z>
- Lau, J.H., Abdin, E., Jeyagurunathan, A. et al. (2021). The association between caregiver burden, distress, psychiatric morbidity and healthcare utilization among persons with dementia in Singapore. *BMC Geriatr*, 21, 67. <https://doi.org/10.1186/s12877-021-02014-2>
- Leung, Lo, S. K., Leung, A. Y., Lou, V. W., Chong, A. M., Kwan, J. S., Chan, W. C., & Chi, I. (2017). Prevalence and correlates of abuse screening items among community-dwelling Hong Kong Chinese older adults: Elder abuse in Hong Kong. *Geriatrics & Gerontology International*, 17(1), 150–160. <https://doi.org/10.1111/ggi.12655>
- Liu, Z., Heffernan, C., & Tan, J. (2020). Caregiver burden: A concept analysis. *International journal of nursing sciences*, 7(4), 438–445. <https://doi.org/10.1016/j.ijnss.2020.07.012>
- Lou, V. W., Lau, B. H. P., & Cheung, K. S. L. (2015). Positive aspects of caregiving (PAC): Scale validation among Chinese dementia caregivers (CG). *Archives of gerontology and geriatrics*, 60(2), 299-306.
- National Institute of Ageing. (2022). *Elder Abuse*. <https://www.nia.nih.gov/health/elder-abuse>
- Robinson, B.C. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, 38, 344-348.
- Social Welfare Department, (2022). *Services for Prevention and Handling of Elder Abuse*. [https://www.swd.gov.hk/en/index/site\\_pubsvc/page\\_elderly/sub\\_csselderly/id\\_serabuseelder/](https://www.swd.gov.hk/en/index/site_pubsvc/page_elderly/sub_csselderly/id_serabuseelder/)
- The HSBC Life (International) Limited, the Sau Po Centre on Ageing at The University of Hong Kong & the Women’s Foundation. (2020). *Eldercare Hong Kong Working dementia caregivers: Challenges and Needs Full Report 2020*. [https://retailbank.hsbc.com.hk/media/5590/hsbclife\\_dementiafullreport\\_en\\_fulllayout\\_v6\\_201124\\_final.pdf](https://retailbank.hsbc.com.hk/media/5590/hsbclife_dementiafullreport_en_fulllayout_v6_201124_final.pdf)
- World Health Organization (WHO). (2022). *Abuse of Older People*. <https://www.who.int/news-room/fact-sheets/detail/abuse-of-older-people>

Yon, Y., Mikton, C. R., Gassoumis, Z. D., & Wilber, K. H. (2017). Elder abuse prevalence in community settings: a systematic review and meta-analysis. *The Lancet. Global health*, 5(2), 147–156. [https://doi.org/10.1016/S2214-109X\(17\)30006-2](https://doi.org/10.1016/S2214-109X(17)30006-2)


Yon, Y., Ramiro-Gonzalez, M., Mikton, C. R., Huber, M., & Sethi, D. (2019). The prevalence of elder abuse in institutional settings: a systematic review and meta-analysis. *European Journal of Public Health*, 29(1), 58–67. <https://doi.org/10.1093/eurpub/cky093>

Yu, H., Wang, X., He, R., Liang, R., & Zhou, L. (2015). Measuring the Caregiver Burden of Caring for Community-Residing People with Alzheimer's Disease. *PloS one*, 10(7), 0132168. <https://doi.org/10.1371/journal.pone.0132168>

Yue, P., Fu, S., & Shang, S. (2006). Reliability and validity of the caregiver burden inventory. *Chinese Mental Health Journal*, 20(8), 562-564.

Zarit, S.H., Reeve, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20(6), 649-655.

-- End of Chapter 2 --

 The logo for Jockey Club Cadenza e-Tools for Elder Care. It features the text 'Jockey Club' at the top, 'Cadenza' in a large, stylized font with a musical note, 'e-Tools' in a smaller font, and 'for Elder Care' below it. At the bottom, there is Chinese text: '賽馬會流金箱護老有道'.	File	Handout – Caregiver Stress - Chapter 2
	Copyright	© 2023 Jockey Club CADENZA e-Tools for Elder Care. All Rights Reserved.
	Page	16