











# **Dementia Trends:**

# Impact of the Ageing Population and Societal Implications for Hong Kong

by

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CADENZA

# **CADENZA: A Jockey Club Initiative for Seniors**

CADENZA: A Jockey Club Initiative for Seniors is a HK\$ 380 million project initiated and funded by The Hong Kong Jockey Club Charities Trust in light of a rapidly ageing population. The Faculty of Social Sciences of The University of Hong Kong and the Faculty of Medicine of The Chinese University of Hong Kong are the project partners. CADENZA aims at creating an elder-friendly community which fosters positive community attitudes towards older people and continually improves the quality of care and quality of life for Hong Kong's elderly.

CADENZA is an acronym for "Celebrate their Accomplishments; Discover their Effervescence and Neverending Zest as they Age." In classical music, a 'Cadenza' is an extended virtuosic section, usually near the end of a movement in a concerto. The word is used figuratively to describe the apex of one's life and the celebration of a lifetime's accomplishments.

## CADENZA has 4 main components:

- 1. **Community Projects** are innovative and sustainable service models designed to cope with the changing needs of seniors. One of the innovative projects is the establishment of The Jockey Club CADENZA Hub in Tai Po, which is an integrated primary health and social care centre for the old and the soon-to-be-old.
- Leadership Training and Research is to nurture academic leadership in gerontology, and to conduct research to advance gerontological knowledge and to evaluate the outcomes of different CADENZA projects.
- 3. *Public Awareness and Public Education Programmes* promote positive ageing and highlight important issues pertaining to the elderly population, covering 6 themes: (i) health promotion and maintenance, (ii) health and social services in Hong Kong, (iii) living environment, (iv) financial and legal issues, (v) quality of life and quality of dying, and (vi) age disparities.
- 4. *Training Programme* includes on-line courses, workshops and public seminars to train different levels of professional front-line workers, care givers and the general public.

The findings covered by this report are part of the series "Challenges of population ageing on disease trends and burden" carried out by CADENZA in collaboration with the Department of Community Medicine, the School of Public Health of The University of Hong Kong. This series utilises existing data to estimate the effect of the ageing population on the impact of various chronic diseases on individuals and society as a whole. The current volume of the series focuses on dementia. This report is made available to the public with the compliments of The Hong Kong Jockey Club Charities Trust.

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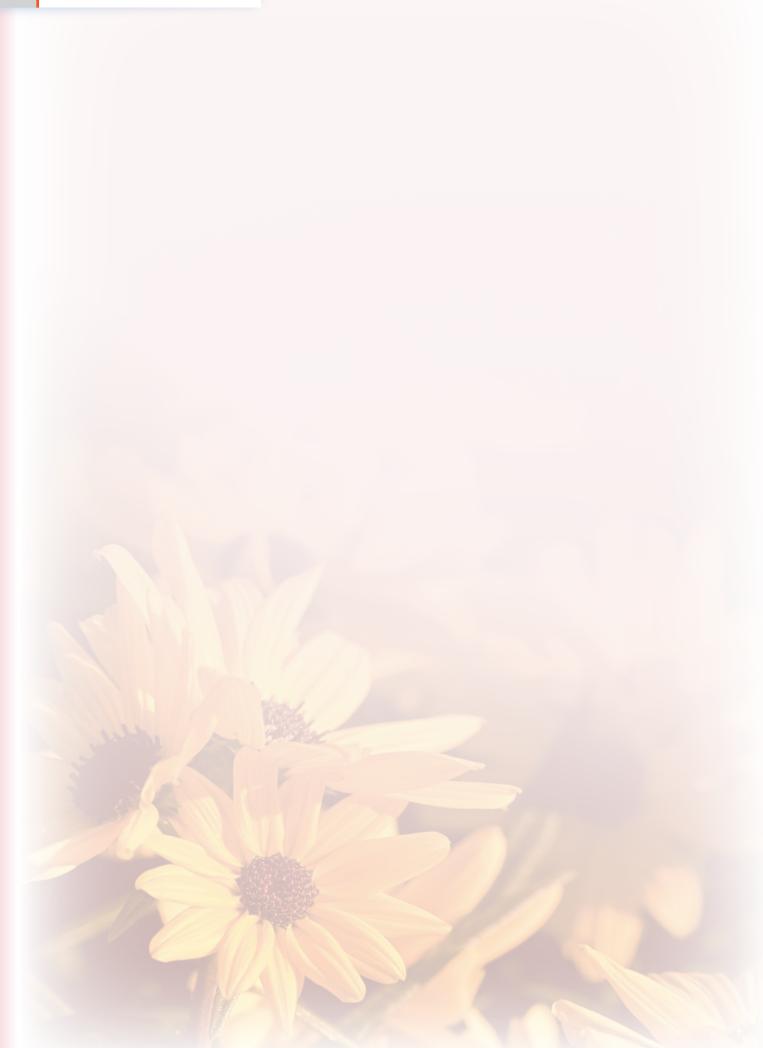
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Preface

# **Preface**

With the prevalence of ageing populations all over the world, the increase in the numbers of people with dementia has been described as a 'tidal wave on the horizon' (Sabat, 2009), in that it is a chronic disease that is one of the major contributors to disability and increases the burden to caregivers as well as health and social care systems. The Hong Kong population is ageing rapidly, such that the population aged 65 and above nearly doubled during the past two decades. It is projected that in 2036, there will be 2.3 million older people in Hong Kong (Census and Statistics Department of Hong Kong Special Administrative Region, 2007b, 2009a). Although it is known that dementia becomes more prevalent with increasing age, a more accurate assessment of the impact of the disease can be attempted by examining the trends in incidence and mortality over a number of years, in addition to simple consideration of the age-related prevalence. This report reviews the trends in dementia prevalence, incidence and mortality over ten years in Hong Kong, including a comparison with other developed countries and estimation of direct and indirect costs. The consequence of increasing numbers of people with dementia in Hong Kong is discussed from society's, caregivers' and patients' point of view. The need for the formulation of a dementia strategy for Hong Kong is examined consequent to the estimation of the magnitude of the problem.



# **Executive Summary**



# **Executive Summary**

Dementia is an age-related condition, with a prevalence rate that nearly doubles for every five years after the age of 65. In Hong Kong, the number of people aged 65 and above is rapidly increasing and it is projected that there will be 2.3 million people aged 65 and above in 2036. Hence, the prevalence of dementia is expected to increase very significantly, and the consequent increased disability burden and costs of long term health and social care will be substantial. The demand for informal caregivers is heavy. However, due to population ageing, the oldest old support ratio (population aged 50-74: population aged 85+) has been decreasing as evidenced in the past two decades. The decreasing ratio implies each informal caregiver is caring for more oldest old people. At the same time, even if there is no increasing trend in the age-specific prevalence rate of dementia, the number of older people who have dementia can be expected to increase over the years due to ageing demographic changes. Given the shrinking pool of informal caregivers and the expanding population with dementia, a question of how to maintain continual care for people with dementia arises. This report reviews the trends in dementia prevalence, incidence and mortality over ten years in Hong Kong, including a comparison with other developed countries and an estimation of burden of

Dementia is an age-related condition. Given the shrinking pool of informal caregivers and the expanding population with dementia, maintaining continual care for people with dementia is an important issue to be tackled.

the disease as well as the current and future economic costs. It also identifies constraints and suggests ways to improve dementia services.

# **Prevalence**

Based on clinical diagnoses, two prevalence studies showed an increasing trend in dementia prevalence from 1995 to 2005-2006. In 1995, about 4.5% of people aged 70 and above in the community had dementia. The prevalence rates of dementia increased with age and approximately doubled for every five years until around age 90. In 2005-2006, the prevalence rate of dementia among people aged 70 and above in the community was 9.3%. About 1 in 3 (32.1%) of the community-dwelling population aged 85 and above had dementia. Based on the prevalence rates of clinically diagnosed dementia in 2005-2006, the number of

cases for community-dwelling people aged 60 and above is estimated to increase from 0.09 million in 2010 to 0.23 million in 2036.

The number of community-dwelling people with dementia aged 60 and above is estimated to increase from 0.09 million in 2010 to 0.23 million in 2036.

The prevalence of dementia in institutional care is also substantial. A study of the prevalence of dementia found that the prevalence rate of clinically diagnosed dementia among people aged 70 and above living in institutions was 17.4% in 1995. A recent survey found that the prevalence rate of self-reported

The number of people aged 60 and above who have dementia and live in institutions is estimated to increase from 0.02 million in 2010 to 0.05 million in 2036.

dementia among people aged 60 and above living in institutions was 30.7% in 2008. Hence, the number of people with dementia aged 60 and above living in institutions is estimated to increase from 0.02 million in 2010 to 0.05 million in 2036.

The prevalence rates of clinically diagnosed dementia in Hong Kong were comparable with studies in Japan, but were higher than those reported in China and Singapore and lower than those reported in the United States. Discrepancy between studies may be due to the difference in age structure, the number of subjects living in institutions, vascular risk profile, and diagnostic criteria of dementia.

# **Incidence**

There is not a great deal of information on the local trend in incidence of dementia. Based on self-reported doctor diagnosed dementia, a cohort study in 1991-1992 found 7.9 per 1,000 subjects aged 70 and above reported dementia in a 36-month follow-up period (2.8 per 1,000 person-years). There was no obvious difference in the incidence rates between males and females aged less than 80, but females aged 80 and

above tended to have a higher incidence rate of dementia (18.3 per 1,000) than their male counterparts (6.2 per 1,000). These data, however, need to be interpreted with caution because self-reported data may undercount those in whom dementia has not been diagnosed and thus leading to an underestimation of the incidence of dementia.

From a 1991-1992 cohort, the annual incidence rate of dementia among the population aged 70 and above in Hong Kong was about 2.8 per 1,000 person-years.

# **Mortality**

Dementia is the tenth most common cause of mortality, approximately 300 people died from dementia in 2007, accounting for 0.8% of all deaths in Hong Kong. Although the age-standardised mortality rate from dementia among people aged 60 and above remained stable between 2003 (30.5 per 100,000) and 2007 (29.0 per 100,000), the number of deaths from dementia increased gradually among those aged 60 and above during the same period, probably driven by an ageing population. Standardised to the WHO standard

Dementia is the tenth most common cause of mortality, accounting for 0.8% of all deaths in Hong Kong in 2007.

population, the age-standardised mortality rate for dementia in Hong Kong was lower than the United States, the United Kingdom, Australia, and China, but higher than Singapore and Japan.

# **Disability burden**

Dementia is associated with significant functional disability among older people and thereby placing a large burden on patients, caregivers and society. The burden of disease from dementia is calculated from the prevalence of dementia, deaths from dementia and global disability weights. In 2006, about 286,000 years of healthy life (Disability-Adjusted Life Years, DALYs) were lost due to dementia among the population aged 60 and above in Hong Kong. The majority of the burden was due to disability, with about 284,000 Years Lost due to Disability (YLDs) making up 99.3% of DALYs. The remaining 0.7% of the burden was due to the estimated premature mortality, 2,000 Years of Life Lost (YLLs) from dementia.

About 286,000 years of healthy life (Disability-Adjusted Life Years, DALYs) were lost due to dementia among population aged 60 and above in Hong Kong in 2006.

# **Economic burden**

In addition to the disability burden, the economic burden on the health care and social services systems is also substantial. We examined the direct costs and indirect costs of caring for dementia patients in 2010 and 2036. Examples of direct costs include costs of hospitalisation and institutional care, while costs of

informal care are examples of indirect costs. Institutional care and informal care are the major components for the costs of dementia. In 2010, the cost of institutional care among people aged 60 and above with dementia was estimated at around HK\$ 1,624 million, based on a prevalence estimate of 105,069 people with dementia in Hong Kong in 2010. By 2036, the cost of institutional care would increase by 1.6 times to around

HK\$ 4,212 million per year. Costs of informal care are also projected to increase as the prevalence of dementia grows. The cost of informal care was estimated to be around HK\$ 10,368 million in 2010 and would increase to over HK\$ 27,000 million by 2036. These estimates only include part of the costs involved in caring for dementia patients.

The costs of institutional care and informal care among dementia patients aged 60 and above are estimated to be around HK\$ 1,624 million and HK\$ 10,368 million in 2010, respectively.

# **Conclusions and recommendations**

Because of the increasing number of people suffering from dementia, the high disability burden of dementia and costs of caring for dementia patients have an enormous impact on the health care and social services systems. Therefore the formulation of a dementia care strategy as part of a care of the elderly strategy would be important for Hong Kong, in view of the magnitude of the dementia burden. Four elements of the strategy are:

- Education and training to both the lay public and health care and social professionals.
- Comprehensive care and support for dementia patients and their caregivers.
- Co-payment service as an alternative mode of delivery.
- Increase in dementia research.

In view of the magnitude of the dementia burden, the formulation of a dementia care strategy as part of a care of the elderly strategy would be important for Hong Kong.



# Chapter 1

# Introduction



## 1.1 Overview

Dementia is referred to as a group of progressive diseases of the brain. These diseases are characterized by an irreversible decline in cognitive and intellectual function such as memory, comprehension, learning, ability to think and calculate, as well as language expression and problem solving. Patients gradually deteriorate with impaired self-care capability, some also with mood and behavioural disorders.

Introduction

In the early stage of the disease, patients tend to be increasingly forgetful, gradually confused with time, places and persons. There is memory loss and the knowledge acquired in the later stage of life is the first to be affected. However, basic capabilities, such as toilet habits and recognition of immediate family members are preserved. As the disease progresses, patients may lose language capability, cannot recognize family members, become incontinent and completely dependent on others for daily activities, thereby imposing a burden to the family caregivers. With good home care, these patients can survive up to 15-20 years after the onset of illness. In advanced dementia, patients become stuporous and bedridden. Premature death may occur due to aspirated pneumonia or bone fracture after a fall.

The most common cause of dementia is Alzheimer's disease, accounting for 50-70% of all dementias worldwide. The second common cause is vascular dementia resulting from multiple minor strokes. This accounts for 30% of elders with dementia. Lewy bodies dementia comprises about 10% of dementia cases and is distinguished by abnormal brain cells (Lewy bodies) which can be seen under a microscope. Fronto-temporal dementia, including Pick's disease, is less common, accounting for 5% of all dementia cases. These have in common the degeneration of the frontal and temporal lobes. Other causes can be due to brain tumors, severe brain trauma, brain infection, vitamin B12 deficiency, drug and alcohol abuse and severe thyroid deficiency.

Alzheimer's disease has been called primary degenerative dementia. It is referred to as 'degenerative' because the brain cells wither away and die. This disrupts the production and distribution of certain chemicals called neurotransmitters that carry messages within the brain. The disease is rare among people at 40-50 years of age. It increases at 60-65 years, reaching a peak at 80

years and above. Alzheimer's disease has been found to be prevalent in people with apolipoprotein E type 4 allele gene. However, inheriting this gene does not always result in Alzheimer's disease (Corder *et al.*, 1993). Researchers in India believe some external factors are involved in interacting with the gene to cause Alzheimer's disease. Increasingly, reports suggest that the use of antioxidants such as vitamin E, vitamin B and lipid–lowering agents have been associated with a reduction of the risk of Alzheimer's disease (World Health Organization (WHO), 2006). At this stage, the external factors that precipitate Alzheimer's disease remain to be proven.

Vascular dementia is a degenerative cerebrovascular disease that leads to a progressive decline in memory and cognitive functioning. It occurs when the blood supply carrying oxygen and nutrients to the brain is interrupted by a blocked or diseased vascular system. Vascular dementia generally affects people between the ages of 60 and 75, and affects more men than women. The sudden onset of symptoms may be a sign of this dementia. Vascular dementia severely impacts memory and cognitive functioning. Nevertheless, vascular dementia is preventable by adopting a healthy lifestyle and rigidly controlling blood pressure and diabetic condition.

Dementia is often associated with functional disabilities and behavioural symptoms, and this often results in a heavy burden for caregivers over several years. Caring for a person with dementia over long periods can have both physical and psychological impacts. The financial costs of caring for people with dementia, particularly informal care, are also substantial. Access to comprehensive care and support, training and respite services remain key needs for informal caregivers and thereby relieving the burden on informal caregivers and improving the quality of life and quality of care for those with dementia and their caregivers.

# 1.2 Diagnosis and severity classification

There is no simple test to diagnose dementia. The diagnostic process may involve an initial screening and assessment followed by a comprehensive clinical evaluation. Initial screening and assessment for dementia is generally initiated when a patient or his/her caregiver expresses concern about symptoms or the clinician notices signs associated with dementia such as a progressive decline in memory or a decrease in ability to perform daily activities.

A variety of screening questionnaires exists to screen cognitive status for deficits that are considered pathological. The most commonly used is the Mini-Mental State Examination (MMSE) (Folstein et al., 1975). It is not diagnostic of dementia but it evaluates various dimensions of cognition function and is useful for documenting subsequent decline. MMSE scores range from 0 to 30, the higher the score the better cognitive performance. People scoring below the cutoff point on the MMSE should undergo further clinical evaluation by a neurologist, geriatrician, psychiatrist or other medical professional to confirm or reject a diagnosis of dementia. The Clock Drawing Test is also popular because it can assess a wide range of functions in addition to memory, including comprehension, planning, motor programming and executive control, global attention, visual memory and reconstruction, concentration and visuo-spatial representation (Sunderland et al., 1989). The Psychogeriatric Assessment Scales (PAS) provide an assessment of both dementia and depression (Jorm et al., 1995). The Alzheimer's Disease Assessment Scale (ADAS) – Cognitive and Non-Cognitive Sections (ADAS-Cog, ADAS-Non-Cog) were designed specially to evaluate all aspects of Alzheimer's disease (Rosen et al., 1984). There also exist some screening tests which are administered to the informant. For example, the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) is a questionnaire administered to an informant about changes in the everyday cognitive function of an elderly person and aims to assess cognitive decline independent of premorbid ability (Jorm and Jacomb, 1989).

Generally, a comprehensive clinical evaluation includes a clinical interview (covering medical history and current situation) following a combination of neuropsychological, behavioural and functional assessments. Neuropsychological assessment considers a specific domain of cognition such as comprehension, insight and judgment. Behavioural assessment considers the non-cognitive aspects of dementia which include personality, mood, psychotic symptoms and behaviours of concern, as well as sleep, eating and sexual disorders. Functional assessment includes a series of simple tasks to evaluate the patient's executive functioning. According to the American Psychiatric Association, dementia is diagnosed on the basis of Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria, which require the presence of multiple cognitive deficits in addition to memory impairment. The cognitive deficits in the criteria cover several areas, including aphasia (language disturbance), apraxia (impaired ability to carry out motor activities despite intact motor function), agnosia (failure to recognize or identify objects despite intact sensory function), and disturbance in executive function (planning, organizing, sequencing, abstracting). The latest version of the DSM criteria was DSM-IV-TR which was published in 2000 (American Psychiatric Association, 2000).

Once dementia syndrome is diagnosed, the diagnosis of a subtype is important because it may determine the possible kind of treatment. The diagnosis of Alzheimer's disease is based on the criteria of the National Institute of Neurological Disorders and Stroke-Alzheimer Disease and Related Disorders (NINCDS-ADRDA) Work Group (McKhann *et al.*, 1984). Modifications to the criteria have been proposed recently (Dubois *et al.*, 2007). Vascular dementia is commonly diagnosed according to the criteria of the National Institute of Neurological Disorders and Stroke-Association Internationale pour la Recherche et l'Enseignement en Neurosciences (NINDS-AIREN) International Workshop (Román *et al.*, 1993). Clinical diagnostic criteria for Lewy body dementia are reported in the third report of the dementia with Lewy bodies (DLB) consortium (McKeith *et al.*, 2005).

Blood tests may also be used to rule out treatable causes of dementia and identify signs of stroke or other disorders than can contribute to dementia. These tests include a complete blood count, glucose levels, thyroid-stimulating hormone, serum electrolytes, serum creatinine, vitamin B12, and liver function tests. Structural neuroimaging with either a computed tomography scan (CT scan) or magnetic resonance imaging (MRI) in the initial evaluation is also used to confirm or eliminate other causes of cognitive impairment, and for differential diagnosis of dementia (Ross and Bowen, 2002; Geldmacher, 2004; American Psychiatric Association, 2007).

The progression of dementia is normally described in three stages: mild, moderate and severe. The Clinical Dementia Rating (CDR) is one of the gold standards of global rating of dementia. Six domains are assessed: memory; orientation; judgment and problem solving; community affairs; home and hobbies; and personal care. CDR ratings are 0 for healthy people, 0.5 for questionable dementia and 1, 2, 3 for mild, moderate and severe dementia as defined in the scale (Hughes *et al.*, 1982). The Hierarchic Dementia Scale (HDS) also provides an assessment of the severity of dementia. It covers nine major ability areas: orientation, observation, memory, praxis, gnosis, language, concentration, cognition and motor function, in six subtests. The maximum score for the whole scale is 200. A person with very mild dementia would score around 160; someone with very severe dementia scores less than 40 (Cole *et al.*, 1983). The Global Deterioration Scale (GDS) was also designed to classify dementia severity. It is made up of detailed clinical descriptions of seven major clinically distinguishable stages, ranging from normal cognition to very severe dementia (Reisberg *et al.*, 1982).

# 1.3 International Classification of Disease (ICD)

The International Statistical Classification of Disease and Related Health Problems (ICD) is published by the World Health Organization (WHO) for the international standard diagnostic classification of disease. The ICD is commonly used to classify diseases and other health problems on records including death certificates and hospital discharge records. According to the Global Burden of Disease (GBD) 2000 Study (Mathers and Leonardi, 2003), the ICD codes for Alzheimer's disease and other dementias are:

- ICD 9<sup>th</sup> version (ICD-9): 290, 330, 331
- ICD 10<sup>th</sup> version (ICD-10): F01, F03, G30, G31

# 1.4 Data quoted in this report

This report examines all types of dementia together, otherwise the specific type of dementia is explicitly stated. In the survey data included in this report, the definition of dementia is either self-reported past diagnosis of dementia by a doctor or clinically diagnosed dementia based on clinical evaluation and criteria.

For mortality statistics, the ICD is used for classifying dementia in Hong Kong. Before 2001, deaths due to dementia were identified by ICD-9. However, many deaths due to dementia were not coded accordingly in the ICD-9 system (Centre for Health Protection, Department of Health of Hong Kong Special Administrative Region, 2005). Hence, this report reviews only trends in dementia mortality in recent years.

As the statistics quoted in this report were compiled from different sources, the conceptualization and compilation methods could vary considerably across studies. The comparisons presented in this report, therefore, can only be interpreted in a broad sense. It is recommended that readers consult the cited references for the meta-data of the studies.

# Chapter 2

# Worldwide Trends and Burden of Dementia



# Worldwide Trends and Burden of Dementia

# 2.1 Prevalence worldwide

According to the latest GBD report by the WHO published in 2004, there were 24.2 million people with dementia worldwide (WHO, 2008a). The worldwide prevalence rate of dementia decreased from 0.6% in 2000 to 0.4% in 2002, whilst between 2002 and 2004, the respective figures remained more or less the same (Table 2.1) (Mathers *et al.*, 2002; WHO, 2004b, 2008a).

	2000	2002	2004
Prevalence rate	0.6%	0.4%	0.4%
Number of people with dementia	37.4 million	22.5 million	24.2 million

Europe had the highest dementia prevalence rate (0.9%) among all WHO sub-regions, followed by the Americas (0.6%) and Western Pacific (0.4%) (WHO, 2008a).

Recently, an international group of experts from Alzheimer's Disease International has attempted to estimate the worldwide prevalence of dementia in 2010 and 2050. They used United Nations population estimates to produce estimates for all types of dementia for five age bands from 60 to 84 years and for those aged 85 and above. It was projected that the number of people with dementia worldwide would increase from 35.6 million in 2010 to 115.4 million by 2050 (Alzheimer's Disease International, 2009).

A number of age-specific prevalence meta-analyses have also been done to examine the prevalence of dementia. These studies generally show similar results such as increasing rates with age. However, prevalence rates vary markedly from one study to another due to methodological

differences and thus making comparisons difficult. Previously, Jorm *et al.* pooled data from 22 studies (Europe, North America, Australasia and Japan) of moderate to severe dementia carried out between 1945 and 1985 and estimated that the prevalence rates increased with advancing age and approximately doubled for every five years until around age 95 (Jorm *et al.*, 1987). Hofman *et al.* pooled data from 12 European studies carried out between 1980 and 1990 and gave very similar figures (Hofman *et al.*, 1991). Lobo *et al.* pooled data from 11 European studies of mild to severe dementia carried out in the 1990s (the EURODEM study) and estimated that prevalence rates for dementia nearly doubled for every five years of age and that females had higher rates, particularly in the older age groups (Lobo *et al.*, 2000). The age-specific prevalence rates for dementia from each of these sources are shown in Table 2.2.

Table 2.2 Prevalence rates of dementia estimated from different studies, by age group, 1987-2000

	Age group						
Data source	65-69	70-74	75-79	80-84	85-89	90-94	95+
Jorm <i>et al</i> . (1987)	1.4%	2.8%	5.6%	10.5%	20.8%	38.6%	
Hofman <i>et al</i> . (1991)	1.4%	4.1%	5.7%	13.0%	21.6%	32.2%	34.7%
Lobo et al. (2000)							
Male	1.6%	2.9%	5.6%	11.0%	12.8%	22.1	1%*
Female	1.0%	3.1%	6.0%	12.6%	20.2%	30.8	3%*

<sup>\*</sup> Figures for people aged 90 and above

# 2.2 Incidence worldwide

Statistics on the incidence of dementia are sparse when compared with the prevalence statistics. Fratiglioni *et al.* carried out a meta-analysis of the age-specific incidence rates of all dementias based on data from eight European studies reporting age-specific incidence data. The pooled incidence rates of dementia increased dramatically with age for both genders, with the rate among those aged 65 to 69 being 2.4 per 1,000 person-years and among those aged 90 and above being 70.2 per 1,000 person-years. Females aged 80 and above tended to have a higher incidence rate of dementia than their male counterparts (Table 2.3) (Fratiglioni *et al.*, 2000).

Table 2.3 Incidence rates of dementia (per 1,000 person-years) from the meta-analysis for European studies, by age group and sex, 2000

Age group	Male	Female	Total
65-69	2.4	2.5	2.4
70-74	6.4	4.7	5.5
75-79	13.7	17.5	16.0
80-84	27.6	34.1	30.5
85-89	38.8	53.8	48.6
90+	40.1	81.7	70.2

Data source: Fratiglioni et al. (2000)

Mathers and Leonardi attempted to estimate the worldwide incidence rates of dementia for the GBD epidemiological regions in 2000. Using the World Standard Population as the standard, the worldwide age-standardised incidence rates of dementia were estimated to be 88.8 per 100,000 for males and 112.4 per 100,000 for females. Females tended to have higher incidence rates of dementia than their male counterparts at all WHO sub-regions. Europe region A (EURO A) had the highest dementia incidence rate (males: 97.8 per 100,000, females: 124.8 per 100,000) among all WHO sub-regions, followed by the Americas region A (AMRO A) (males: 97.7 per 100,000, females: 122.8 per 100,000) and Western Pacific region A (WPRO A) (males: 96.8 per 100,000, females: 120.3 per 100,000) (Table 2.4) (Mathers and Leonardi, 2003).

Table 2.4 Estimated age-standardised\* incidence rates for dementia (per 100,000), by WHO epidemiological sub-region, 2000

WHO sub-region	Male	Female
AFRO D Algeria, Angola, Benin, Burkina Faso, Cameroon, Cape Verde, Chad, Comoros, Djibouti, Equatorial Guinea, Gabon, Gambia, Ghana, Guinea, Guinea-Bissau, Liberia, Madagascar, Mali, Mauritania, Mauritius, Niger, Nigeria, Sao Tome and Principe, Senegal, Seychelles, Sierra Leone, Somalia, Sudan, Togo	67.2	81.0
AFRO E Botswana, Burundi, Central African Republic, Congo, Côte d'Ivoire, Democratic Republic of the Congo, Eritrea, Ethiopia, Kenya, Lesotho, Malawi, Mozambique, Namibia, Rwanda, South Africa, Swaziland, Uganda, United Republic of Tanzania, Zambia, Zimbabwe	67.6	79.4

WHO sub-region	Male	Femal
AMRO A Canada, United States of America	97.7	122.8
AMRO B Antigua and Barbuda, Argentina, Bahamas, Barbados, Belize, Brazil, Chile, Colombia, Costa Rica, Cuba, Dominica, Dominican Republic, El Salvador, Grenada, Guyana, Honduras, Jamaica, Mexico, Panama, Paraguay, Saint Kitts and Nevis, Saint Lucia, Saint Vincent and the Grenadines, Suriname, Trinidad and Tobago, Uruguay, Venezuela	95.8	115.5
AMRO D Bolivia, Ecuador, Guatemala, Haiti, Nicaragua, Peru	94.3	113.3
EMRO B Bahrain, Cyprus, Iran (Islamic Republic of), Jordan, Kuwait, Lebanon, Libyan Arab Jamahiriya, Oman, Qatar, Saudi Arabia, Syrian Arab Republic, Tunisia, United Arab Emirates	69.9	82.3
EMRO D Egypt, Iraq, Morocco, Yemen	67.1	80.3
EURO A Andorra, Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Israel, Italy, Luxembourg, Malta, Monaco, Netherlands, Norway, Portugal, San Marino, Slovenia, Spain, Sweden, Switzerland, United Kingdom	97.8	124.8
EURO B1 Albania, Bosnia and Herzegovina, Bulgaria, Georgia, Poland, Romania, Slovakia, The former Yugoslav Republic of Macedonia, Turkey, Yugoslavia	96.7	117.5
EURO B2 Armenia, Azerbaijan, Kyrgyzstan, Tajikistan, Turkmenistan, Uzbekistan	95.0	118.1
EURO C Belarus, Estonia, Hungary, Kazakhstan, Latvia, Lithuania, Republic of Moldova, Russian Federation, Ukraine	88.7	117.1
SEARO B Brunei Darussalam, Indonesia, Malaysia, Philippines, Singapore, Sri Lanka, Thailand	93.8	108.9
SEARO D Afghanistan, Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan	66.9	81.9
WPRO A Australia, Japan, New Zealand	96.8	120.3
WPRO B1 China, DPR Korea, Mongolia, Republic of Korea	93.6	113.1
WPRO B2 Cambodia, Lao People's Democratic Republic, Myanmar, Vietnam	93.8	112.2
WPRO B3 Cook Islands, Fiji, Kiribati, Marshall Islands, Micronesia (Federated States of), Nauru, Niue, Palau, Papua New Guinea, Samoa, Solomon Islands, Tonga, Tuvalu, Vanuatu	92.9	106.2
World	88.8	112.4

Data source: Mathers and Leonardi (2003)

# 2.3 Mortality worldwide

In 2004, dementia was the sixth leading cause of death in high-income countries\* and there were approximately 0.5 million people who died from dementia worldwide (WHO, 2008b). The proportion of deaths due to dementia worldwide also increased from 0.6% in 2000 to 0.8% in 2004 (Mathers *et al.*, 2002; WHO, 2004b, 2008a). It was projected that the number of deaths due to dementia would increase to 0.8 million in 2030 (Table 2.5) (WHO, 2008c).

Table 2.5 Worldwide number of deaths from dementia for years 2000-2004 and projection for 2030

	2000	2002	2004	2030	% change (2004-2030)
Number of deaths due to dementia	0.4 million	0.4 million	0.5 million	0.8 million	61% increase
Proportion of deaths due to dementia among all deaths	0.6%	0.7%	0.8%	1.2%	50% increase
Mortality rate (per 100,000)	6.0	6.4	7.6	9.7	27% increase

Data sources: Mathers et al. (2002); WHO (2004b, 2008a, 2008c)

The worldwide mortality rate for dementia increased slightly from 6.0 per 100,000 in 2000 to 7.6 per 100,000 in 2004 (Mathers *et al.*, 2002; WHO, 2004b, 2008a). The mortality rate for dementia increased sharply with age for both genders, with the rate among males aged 45 to 59 being 1.1 per 100,000 and among those aged 80 and above being 321.7 per 100,000 in 2004. The corresponding figures for females were 0.9 per 100,000 and 414.2 per 100,000. Females aged 80 and above tended to have a higher mortality rate of dementia than their male counterparts (Table 2.6) (WHO, 2008a).

<sup>\*</sup> High income countries include: Andorra, Aruba, Australia, Austria, Bahamas, Bahrain, Belgium, Bermuda, Brunei Darussalam, Canada, Cayman Islands, Channel Islands, Cyprus, Denmark, Faeroe Islands, Finland, France, French Polynesia, Germany, Greece, Greenland, Guam, Iceland, Ireland, Isle of Man, Israel, Italy, Japan, Kuwait, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Netherlands Antilles, New Caledonia, New Zealand, Norway, Portugal, Puerto Rico, Qatar, Republic of Korea, San Marino, Saudi Arabia, Singapore, Slovenia, Spain, Sweden, Switzerland, United Arab Emirates, United Kingdom, United States of America, United States Virgin Islands.

Table 2.6 Worldwide mortality rates for dementia (per 100,000),
by age group and sex, 2004

Age group	Male	Female
45-59	1.1	0.9
60-69	5.6	5.4
70-79	67.4	61.0
80+	321.7	414.2

Data source: WHO (2008a)

The Americas had the highest dementia mortality rate (17.5 per 100,000) among all WHO subregions in 2004, followed by Europe (15.6 per 100,000) and South East Asia (5.5 per 100,000) (WHO, 2008a).

# 2.4 Disability-Adjusted Life Years (DALYs) worldwide

According to the latest GBD study by the WHO, dementia caused more than 11 million Disability-Adjusted Life Years (DALYs) worldwide in 2004 (WHO, 2008a). It was projected that DALYs lost to dementia would be nearly 20 million in 2030 (WHO, 2008c). Because dementia is largely a disease of older people, the burden from dementia is generally greater in high-income countries, where diagnosis and treatment are better and lead to increased life-expectancy. Dementia was the fourth leading cause of DALYs in high-income countries\*, accounting for 3.6% of total DALYs among all high-income countries (WHO, 2008b).

Table 2.7 shows the variation in DALYs lost to dementia throughout the world. Taking into account the population size, Europe had the highest DALYs per 1,000 population (3.5 DALYs per 1,000 population), followed by The Americas (2.5 DALYs per 1,000 population) and Western Pacific (1.9 DALYs per 1,000 population) (WHO, 2008a).

<sup>\*</sup> High income countries include: Andorra, Aruba, Australia, Austria, Bahamas, Bahrain, Belgium, Bermuda, Brunei Darussalam, Canada, Cayman Islands, Channel Islands, Cyprus, Denmark, Faeroe Islands, Finland, France, French Polynesia, Germany, Greece, Greenland, Guam, Iceland, Ireland, Isle of Man, Israel, Italy, Japan, Kuwait, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, Netherlands Antilles, New Caledonia, New Zealand, Norway, Portugal, Puerto Rico, Qatar, Republic of Korea, San Marino, Saudi Arabia, Singapore, Slovenia, Spain, Sweden, Switzerland, United Arab Emirates, United Kingdom, United States of America, United States Virgin Islands.

Table 2.7 Worldwide estimates of DALYs lost to dementia, by region, 2004

Region	DALYs	DALYs per 1,000 population
Africa	0.4 million	0.6
Americas	2.2 million	2.5
Eastern Mediterranean	0.4 million	0.7
Europe	3.1 million	3.5
South East Asia	1.7 million	1.0
Western Pacific	3.4 million	1.9
World	11.2 million	1.7

Data source: WHO (2008a)

# 2.5 Summary

There were 24.2 million people with dementia worldwide in 2004. In 2000, the worldwide age-standardised incidence rates (per 100,000) for dementia were estimated to be 88.8 for males and 112.4 for females. By 2030, the worldwide number of deaths due to dementia was projected to increase from 0.5 million in 2004 to 0.8 million. Dementia caused more than 11 million DALYs worldwide in 2004 and it was projected that DALYs lost to dementia would be nearly 20 million in 2030. Among WHO sub-regions, The Americas had the highest dementia mortality rate and Europe had the highest DALYs lost to dementia per 1,000 population in 2004.



# Chapter 3

# Trends in Dementia Prevalence in Hong Kong



# Trends in Dementia Prevalence in Hong Kong

Hong Kong has a rapidly ageing population. The population aged 65 and above nearly doubled during the past two decades, from 0.5 million in 1988 to 0.9 million in 2008. It is projected that in 2036, there will be 2.3 million people aged 65 and above in Hong Kong (Census and Statistics Department of Hong Kong Special Administrative Region, 2007b, 2009a). With the ageing population, Hong Kong will experience increasingly larger numbers of older people with dementia in the future. This chapter reviews the trends in dementia prevalence and calculates current estimates and future projections of the number of people with dementia in Hong Kong. Prevalence rates reported in previous studies in Hong Kong are also compared with those of other countries.

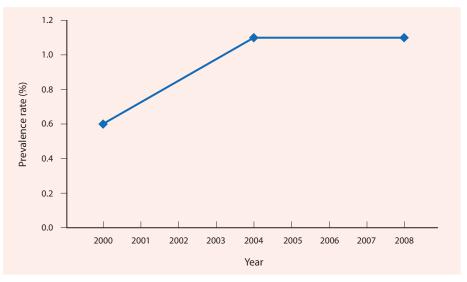
# 3.1 Previous estimates of dementia prevalence

A number of individual epidemiological studies have investigated the prevalence of dementia in older people in Hong Kong. Prevalence estimates of dementia have been based on self-reported data and clinically diagnosed data. However, the prevalence of self-reported dementia was likely to be underestimated particularly when symptoms are mild such that the respondent is not fully aware of his/her condition. Place of residency also has substantial effect on the prevalence reported. For these reasons, previous estimates of dementia prevalence are presented by diagnosis criteria (self-reported versus clinically diagnosed dementia) and place of residency (community versus institutions) in this report.

# 3.1.1 Self-reported dementia among community population

Data were collected from several household surveys, which asked whether the respondent had been told by a doctor that they had dementia, had been diagnosed with dementia in the past or was receiving medical care for dementia. According to self-reported estimates, there was an increasing trend in the prevalence rate of dementia among older people in Hong Kong from 2000 to 2008 (Figure 3.1) (Census and Statistics Department of Hong Kong Special Administrative Region, 2001, 2005, 2009b).

Figure 3.1 Prevalence rate of self-reported dementia among community-dwelling people aged 60 and above, Hong Kong, 2000-2008



Data sources: Census and Statistics Department of Hong Kong Special Administrative Region (2001, 2005, 2009b)

The prevalence rates of dementia increased with age. Based on the Population Health Survey 2003/2004, the prevalence rate of dementia was 0.8% for people aged 65-69 and 5.0% for people in the 85 and above age group (Table 3.1). There was no obvious gender difference in the prevalence rates of dementia (Department of Health of Hong Kong Special Administrative Region and Department of Community Medicine of the University of Hong Kong, 2005).

Table 3.1 Prevalence rates of self-reported dementia among community-dwelling people aged 60 and above in Hong Kong, by age group, 2003-2004

Age group	Prevalence rate	
65-69	0.8%	
70-74	1.4%	
75-79	1.8%	
80-84	6.0%	
85+	5.0%	
65+	2.0%	

Data source: Department of Health of Hong Kong Special Administrative Region and Department of Community Medicine of the University of Hong Kong (2005)

Further estimates of the prevalence rates of dementia based on self-report of previous doctor diagnoses are shown in Table 3.2. However, these estimates are not directly comparable with the previous estimates due to specific sample selection criteria.

Table 3.2 Further estimates of prevalence rates of self-reported	
dementia in older people in Hong Kong, 1991-1992 and 1998-1999	

Year	Age	Sample Characteristics	Prevalence rate	Source
1991-1992	70+	Older people receiving allowance from the government and living in the community or in institutions	2.0%	Ho et al. (1994)
1998-1999	65+	Older people living in the community who could walk independently or with a walking aid	0.3%	Chu <i>et al</i> . (2005)

## 3.1.2 Clinically diagnosed dementia among community population

Studies on the prevalence of clinically diagnosed dementia are scarce in Hong Kong and only two studies have reported the prevalence rates of clinically diagnosed dementia among the community population, one conducted in 1995 (Chiu *et al.*, 1998), and the other in 2005-2006 (Elderly Commission, 2006; Lam *et al.*, 2008). For the 1995 study, elderly aged 70 and above living in Shatin were examined. Using DSM-IV criteria for the diagnosis of dementia, the prevalence rate of dementia among people living in the community was 4.5%. The prevalence rates of dementia increased with age and approximately doubled for every five years until around age 90. For the 2005-2006 study, people aged 60 and above were examined. Using DSM-IV criteria for the diagnosis of dementia, the prevalence rate of dementia among people aged 70 and above was 9.3%. Again, the prevalence rates of dementia increased with age, with the rate among those aged 60 to 64 being 1.2% and among those aged 85 and above being 32.1%.

For the 1995 study, the prevalence rate of dementia among males aged 75 to 84 was higher than that of females of the corresponding age group; but the reverse was true for those aged 85 and above. For the 2005-2006 study, the prevalence rate of dementia among males aged 60 to 64 was higher than that of their female counterparts, but the reverse was true for those aged between 65 and 84. While it is observed that females have higher dementia prevalence rates than males at older ages, more studies are needed to confirm the speculation.

Table 3.3 Prevalence rates of clinical dementia among community-dwelling people aged 60 and above in Hong Kong, by age group and sex, 1995 and 2005-2006

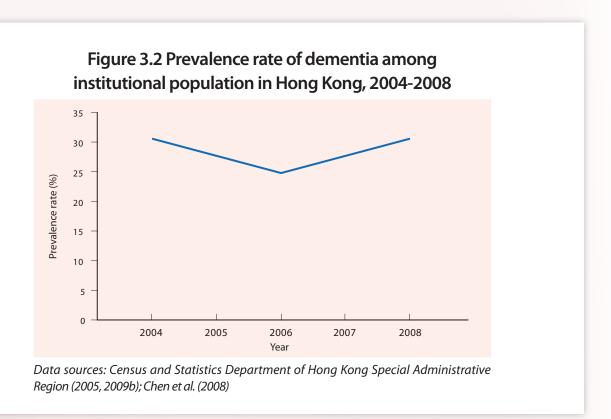
	<b>1995</b> <sup>1</sup>			<b>2005-2006</b> <sup>2</sup>		
Age group	Male	Female	Total	Male	Female	Total
60-64				1.9%	0.4%	1.2%
65-69				1.9%	3.2%	2.5%
70-74	1.6%	1.8%	1.7%	1.6%	5.3%	3.5%
75-79	4.5%	3.8%	4.1%	8.3%	11.4%	9.9%
80-84	11.1%	10.4%	10.7%	12.2%	24.0%	19.0%
85-89	12.0%	22.0%	18.8%	22.10/	22.00/	22.10/
90+	9.8%	29.9%	25.8%	33.1%	32.0%	32.1%
60+				4.2%	9.9%	7.2%
70+			6.1%	8.9%	15.3%	9.3%

Data sources: <sup>1</sup>Chiu et al. (1998); <sup>2</sup>Elderly Commission (2006) and Lam et al. (2008)

The 2005-2006 study included information about dementia severity, which was determined by global Clinical Dementia Rating (CDR) algorithms of 1 to 3, indicating mild to severe dementia. Among the subjects with clinical dementia, 83% had mild dementia, 10% had moderate dementia, and 7% had severe dementia (Elderly Commission, 2006; Lam *et al.*, 2008).

# 3.1.3 Self-reported dementia among institutional population

Because of the disabling impact of dementia, a high proportion of people with severe dementia live in institutions. According to self-reported estimates, the prevalence rate of dementia among the institutional population aged 60 and above in Hong Kong did not change between 2004 (30.7%) and 2008 (30.7%) (Census and Statistics Department of Hong Kong Special Administrative Region, 2005, 2009b). In 2006, a prevalence survey among 43 institutions for the elderly showed that the self-reported past doctor diagnosis of dementia was 24.9% among those aged 60 and above (Figure 3.2) (Chen *et al.*, 2008).



## 3.1.4 Clinically diagnosed dementia among institutional population

To our knowledge, only one study has reported the prevalence rate of clinically diagnosed dementia among people living in institutions in the Shatin district in Hong Kong. According to Chiu *et al.* (1998), the prevalence of clinically diagnosed dementia among the institutional population aged 70 and above (n=176) was 17.4% in 1995 (Chiu *et al.*, 1998).

# 3.2 Current and future estimates of dementia prevalence

Age-sex-specific prevalence of dementia was estimated for community and institutional populations separately. We estimated the total numbers of people with dementia in the community and in institutions in Hong Kong by multiplying the age-sex-specific prevalence rates of clinically diagnosed dementia obtained from the Lam *et al.* study (Elderly Commission, 2006; Lam *et al.*, 2008) to the Hong Kong domestic population; and the self-reported prevalence rates of dementia obtained from the Census and Statistics Department of Hong Kong Special Administrative Region (2009b) to the Hong Kong institutional population, respectively. The proportions of domestic population and institutional population in Hong Kong are assumed to be constant as those in 2008 (Census and Statistics Department of Hong Kong Special Administrative Region, 2009b).

Assuming the age-sex-specific prevalence rates of dementia among the community population remain unchanged, it was estimated that 0.09 million people aged 60 and above living in the community have dementia in Hong Kong in 2010, of whom over 30% are aged 85 and above. Using the same methodology and assuming that the age-sex-specific prevalence rates among the community population and the age-sex-specific proportion of domestic population in Hong Kong remain unchanged until 2036, the number of people aged 60 and above living in the community with dementia would be expected to increase from 0.09 million in 2010 to 0.23 million by 2036 (Table 3.4).

Table 3.4 Projected numbers of people with dementia living in the community in Hong Kong, 2010 and 2036

	2010			2036		
Age group	Male	Female	Total	Male	Female	Total
60-74	7,588	10,237	17,824	11,876	26,582	38,458
75-84	13,652	27,650	41,302	36,514	75,173	111,686
85+	9,856	17,420	27,276	31,101	43,787	74,887
60+	31,096	55,307	86,402	79,490	145,542	225,032

Note: Individual cells may not sum to total due to rounding.

Data source: Authors' calculations

For the institutional population, estimates were based on the assumption that age-sex-specific prevalence rates of dementia remain unchanged. Self-reported prevalence rate of dementia was used instead of clinically diagnosed dementia prevalence rate because it was the best available age-sex-specific dementia prevalence rate among the institutional population. Assuming constant rates and applying these rates to the population in Hong Kong in 2010 and 2036, around 20,000 people aged 60 and above living in institutions were estimated to have dementia in 2010. By 2036, it is projected that there will be around 50,000 people aged 60 and above living in institutions with dementia (Table 3.5).

Table 3.5 Projected numbers of people with dementia living in institutional care homes in Hong Kong, 2010 and 2036

		2010		2036			
Age group	Male	Female	Total	Male	Female	Total	
60-74	1,341	906	2,247	2,390	2,287	4,677	
75-84	2,463	4,304	6,766	6,627	11,690	18,317	
85+	1,806	7,846	9,653	5,700	19,723	25,423	
60+	5,610	13,056	18,666	14,717	33,700	48,417	

Note: Individual cells may not sum to total due to rounding.

Data source: Authors' calculations

Combining the community and institutional populations, the projected number of people aged 60 and above with dementia will increase from 0.11 million in 2010 to 0.27 million in 2036. This corresponds to an increase of 160%. Nevertheless, the above estimates assume the rates of dementia in Hong Kong remain unchanged until 2036, with changing demographic only. The prevalence rates do seem to increase and the above projection is just a conservative estimate. Hence, the number of people with dementia is expected to increase even faster.

#### 3.3 Comparison of prevalence with other countries

A large number of surveys of dementia have been reported all over the world. Since the study populations varied in age structure, the proportion of subjects living in institutions, and diagnostic criteria of dementia, strict comparisons across studies are not possible. Therefore, international comparisons can only be conducted in a broad sense. Selected dementia prevalence studies in Hong Kong, the United States, the United Kingdom, China, Japan, and Singapore using DSM diagnostic criteria are briefly described in Table 3.6. Prevalence estimates based on modelling were not included in the table.

The prevalence rates of dementia across countries varied but all consistently showed a higher rate at older age. Based on DSM criteria, the prevalence rate of dementia among people aged 60 and above in the study of Lam *et al.* (Elderly Commission, 2006; Lam *et al.*, 2008) in Hong Kong was higher than those reported in China (Gao *et al.*, 1999; Zhou *et al.*, 2006; Llibre Rodriguez *et al.*, 2008) and Singapore (Sahadevan *et al.*, 2008), lower than that reported in the United States (Plassman *et al.*, 2007), but comparable to that in Japan (Meguro *et al.*, 2002). Details about age-sex-specific prevalence rates of dementia in individual countries are presented in subsequent sections.

Table 3.6 Prevalence studies on clinically diagnosed dementia (based on DSM) in Hong Kong and selected countries, 1990 to present

Year	Location	Dementia diagnostic criteria	Sample characteristics	Age	Prevalence	Alzheimer's disease %	Vascular dementia %	Source
1995	Hong Kong	DSM-IV	Elders living in the community and in institutions in a district	70+	6.1%	64.6%	29.3%	Chiu <i>et al.</i> (1998)
2005- 2006	Hong Kong	DSM-IV	Elders living in the community	60+ 70+	7.2% 9.3%	63.0% 	20.3% 	Elderly Commission (2006) Lam et al. (2008)
2001- 2003	United States	DSM-III-R and DSM-IV	Elders living in the community at baseline	71+	13.9%	69.9%	17.4%	Plassman <i>et al.</i> (2007)
1990	China	DSM-III-R	Elders living in the community in a region	60+	4.2%	74.8%	20.1%	Gao <i>et al.</i> (1999)
1999- 2000	China	DSM-IV	Elders living in a rural area	50+	2.3%	80.5%	11.0%	Zhou <i>et al.</i> (2006)
2003- 2007	China	DSM-IV	Elders living in urban and rural areas	65+	Urban: 3.0% Rural: 2.4%			Llibre Rodriguez et al. (2008)
1998	Japan	DSM-IV	Elders living in the community in a rural area	65+	8.5%		-	Meguro <i>et al.</i> (2002)
2001- 2003	Singapore	DSM-IV	Elders living in the community or in institutions	50+ 65+	1.4% 3.7%	54.5% 	45.5% 	Sahadevan <i>et</i> al. (2008)

Abbreviation: DSM-III-R, Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised; DSM-IV, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition

Recently, Alzheimer's Disease International has attempted to compare the prevalence of dementia between Hong Kong and selected Asia-Pacific regions in 2005 (Access Economics, 2006). Controlling for the population size, Japan had the highest prevalence rate of dementia in 2005 (1.5%), followed by Australia (1.0%) and Hong Kong (0.9%) (Figure 3.3). It was projected that the prevalence of dementia in Hong Kong would increase from 59,700 people in 2005 to 332,000 people in 2050. This corresponds to an increase of over 450%. By contrast, China started with a large number of people with dementia and would experience an apparently smaller increase over the period. The most rapid growth in dementia prevalence is projected for Singapore (8.5 times the number with dementia in 2050 relative to 2005), while Japan shows the slowest increase in numbers of people with dementia, although 2.6 times the numbers of 2005 by 2050. The prevalence in Australia will approximately triple from 2005 to 2050 (Table 3.7) (Access Economics, 2006).

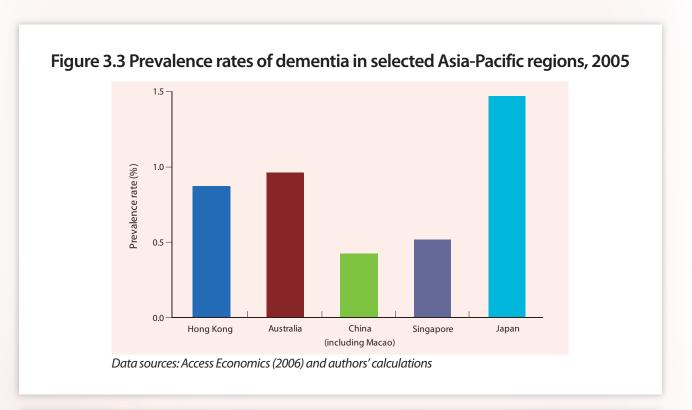


Table 3.7 Number of people with dementia (in thousand) in selected Asia-Pacific regions, 2005-2050

				% change
Asia-Pacific region	2005	2020	2050	(2005-2050)
Hong Kong	59.7	109.2	332.0	456% increase
Australia	195.4	301.3	664.1	240% increase
China (including Macao)	5,541.2	9,596.3	27,004.4	387% increase
Singapore	22.0	52.6	186.9	750% increase
Japan	1,871.2	3,251.3	4,873.1	160% increase

Data source: Access Economics (2006)

#### 3.3.1 United States

In the United States, a population-based study of non-institutionalized individuals was conducted in East Boston in 1982. Using DSM-III and NINCDS-ADRDA criteria, the prevalence rate of Alzheimer's disease was estimated to be 10.3% among those aged 65 and above. The prevalence rates increased with age, with the rate among those aged 65 to 74 being 3.0% and among those aged 85 and above being 47.2% (Evans *et al.*, 1989). Another population-based study examining 856 older people aged 71 and above was conducted in the United States in 2001-2003. Using DSM-III-R and DSM-IV criteria, the prevalence rate of dementia was 13.9%. Again, the prevalence rates increased with age, with the rate among those aged 71 to 79 being 5.0% and among those aged 90 and above being 37.4% (Table 3. 8) (Plassman *et al.*, 2007).

Table 3.8 Prevalence rates of clinically diagnosed dementia in the United States, by age group and sex, 2001-2003

		<u> </u>			
Age group	Male	Female	Total		
71-79	5.3%	4.8%	5.0%		
80-89	17.7%	27.8%	24.2%		
90+	44.6%	34.7%	37.4%		
71+	11.1%	15.7%	13.9%		

Data source: Plassman et al. (2007)

#### 3.3.2 United Kingdom

In the United Kingdom, a prevalence study was conducted in community-dwelling and institutional populations living in four urban areas and two rural areas. Using Automated Geriatric Examination Assisted Taxonomy (AGECAT) organicity and Geriatric Mental State (GMS) criteria, the prevalence rate of dementia was estimated to be 6.6% among those aged 65 years and above (standardised to the England and Wales population 1991) (The Medical Research Council Cognitive Function and Ageing Study, 1998). In 2007, the Alzheimer's Society attempted to estimate the prevalence of dementia in the United Kingdom using previous prevalence figures and the United Kingdom population. It was projected that the number of people with dementia in the United Kingdom would increase from 0.7 million in 2005 to 1.7 million in 2051. The prevalence rates of dementia would increase with age and would double for every five years up to the age group of 85-89. Table 3.9 shows the consensus estimates of prevalence rates of late onset dementia (Alzheimer's Society, 2007).

Table 3.9 Consensus estimates of prevalence rates of late onset dementia in the United Kingdom, by age group and sex, 2005

	<u> </u>	, , , , ,	<u> </u>
Age group	Male	Female	Total
65-69	1.5%	1.0%	1.3%
70-74	3.1%	2.4%	2.9%
75-79	5.1%	6.5%	5.9%
80-84	10.2%	13.3%	12.2%
85-89	16.7%	22.2%	20.3%
90-94	27.5%	29.6%	28.6%
95+	30.0%	34.4%	32.5%

Data source: Alzheimer's Society (2007)

#### 3.3.3 Australia

In Australia, there is a lack of epidemiological study of the age-sex-specific prevalence of dementia. In 2009, Alzheimer's Australia commissioned Access Economics to estimate dementia prevalence rates in Australia using a combination of published epidemiological studies and meta-analyses. It was projected that the number of people with dementia in Australia would increase over 4-fold from approximately 0.2 million people in 2009 to 1.1 million people in 2050. The prevalence rate of dementia was low among people aged less than 65 years and the rates doubled for each progressive five-year age category (Table 3.10) (Access Economics, 2009).

Table 3.10 Estimated prevalence rates of dementia in Australia based on modelling, by age group and sex, 2009

	- ,	-
Age group	Male	Female
60-64	1.2%	0.6%
65-69	1.7%	1.3%
70-74	3.5%	3.3%
75-79	5.8%	6.3%
80-84	12.1%	12.9%
85-89	21.1%	24.4%
90-94	31.5%	35.7%
95+	37.2%	47.3%

Data source: Access Economics (2009)

#### 3.3.4 China

In China, several population-based studies on the prevalence of dementia have been carried out. An early population-based study examining 3,779 urban, suburban, and rural people aged 60 and above was conducted in Shanghai and nearby areas in 1990. Using DSM-III-R criteria, the prevalence rate of dementia was 4.2%. The rate increased with age and was higher in women and in urban residents (Gao *et al.*, 1999). Another population-based study examining 34,807 community-dwelling and institutional population aged 55 and above was conducted in Beijing, Xian, Shanghai, and Chengdu in 1997. Based on clinical examinations, the prevalence rate of dementia (Alzheimer's disease and vascular dementia) among people aged 55 and above was 2.8% (Zhang *et al.*, 2005). Another prevalence study of people aged 50 and above was conducted in Linxian, a rural county, in 1999-2000. Using DSM-IV criteria for the diagnosis of dementia, the prevalence rate of dementia was 2.3% with Alzheimer's disease being more common (80.5%). Again, the prevalence rates increased with age, with the rate among those aged 50 to 54 being

0.3% and among those aged 75 and above being 8.2% (Zhou *et al.*, 2006). Most recently, the 10/66 Dementia Research Group examined the prevalence rates of dementia among people aged 65 and above in Latin America, India, and China in 2003-2007 based on a 10/66 diagnostic dementia algorithm and DSM-IV criteria. In general, the prevalence rate of dementia was higher in urban than in rural China. Using DSM-IV criteria, the crude prevalence rate of dementia in urban China was 3.0%, whereas that for rural China was 2.4%. Using the 10/66 dementia criteria, the crude prevalence rate of dementia was 7.0% for urban China and 5.6% for rural China. The prevalence rates of dementia increased exponentially with age for both genders (Table 3.11) (Llibre Rodriguez *et al.*, 2008).

Table 3.11 Prevalence rates of clinically diagnosed dementia in urban and rural China, by age group, sex and diagnostic criteria, 2003-2007

	10/66 dementia				DSM-IV			
_	Urban		Rural		Urban		Rural	
Age group	Male	Female	Male	Female	Male	Female	Male	Female
65-69	0.0%	2.9%	1.6%	1.6%	0.9%	2.0%	0.1%	1.6%
70-74	3.7%	3.0%	3.1%	4.2%	2.5%	0.5%	2.3%	1.8%
75-79	6.0%	8.0%	9.1%	9.6%	3.4%	2.2%	2.6%	4.8%
80+	14.7%	24.4%	19.6%	14.7%	5.5%	10.1%	8.7%	2.7%
65+ (crude)	7.	0%	5.	6%	3.	.0%	2.	.4%
65+ (age-sex-education-adjusted*)	8.	0%	4.	8%	3.	.1%	2.	.0%

<sup>\*</sup>The standardised rates used the whole 10/66 survey sample as the standard population. Data source: Llibre Rodriguez et al. (2008)

#### 3.3.5 *Japan*

In Japan, a population-based study examining 887 community-dwelling elderly was conducted in Hisayama, a Japanese rural community, in 1985. Using DSM-III diagnostic criteria and CT scan, the prevalence rate of dementia was 6.7% among residents aged 65 and above. The prevalence rates increased with age, with the rate among those aged 65 to 69 being 1.8% and among those aged 85 and above being 38.9%. The prevalence rate among women (7.5%) was slightly higher than that in men (5.4%) (Ueda *et al.*, 1992). Another population-based study examining 1,654 people aged 65 and above was conducted in Tajiri, a typical agricultural area in Japan, in 1998. Using DSM-IV criteria, the prevalence rate of dementia was 8.5%. Again, the prevalence rates increased with age for both genders (Meguro *et al.*, 2002). Based on these two prevalence studies, the prevalence rate of dementia seemed to follow an increasing trend in men but remained stable for women between 1985 and 1998 (Table 3.12).

Table 3.12 Prevalence rates of clinically diagnosed dementia in Japan, by age group and sex, 1985-1998

	(base	1985 <sup>†</sup> d on DSM-III cr	iteria)	1998 <sup>2</sup> (based on DSM-IV criteria)		
Age group	Male	Female	Total	Male	Female	Total
65-69	1.7%	1.9%	1.8%	3.5%	0.9%	
70-74	3.7%	1.4%	2.4%	5.0%	1.9%	
75-79	1.5%	7.0%	4.9%	3.9%	11.0%	
80-84	14.9%	15.3%	15.1%	21.9%	14.7%	
85+	41.7%	38.1%	38.9%	33.9%	39.4%	
65+	5.4%	7.5%	6.7%	9.2%	8.0%	8.5%

Data sources: <sup>1</sup>Ueda et al. (1992); <sup>2</sup>Meguro et al. (2002)

#### 3.3.6 Singapore

In Singapore, the National Mental Health Survey of the Elderly conducted in 2003 examined 1,092 community-dwelling elderly aged 60 and above. Using the AGECAT and GMS criteria, it found the prevalence rates of dementia to be 5.2% for those aged 60 and above, 6.0% for those aged 65 and above, and 13.9% for those aged 75 and above (Chiam *et al.*, 2004). Another survey conducted in 2001-2003 examined 14,817 people aged 50 and above living in the community or institutions. Using the DSM-IV criteria, it found the age-race-adjusted prevalence rate of dementia to be 1.3%. Again, the prevalence rates increased with age (Table 3.13) (Sahadevan *et al.*, 2008).

Table 3.13 Prevalence rates of clinically diagnosed dementia in Singapore, by age group and sex, 2001-2003

	2003 $^{7}$ (based on AGECAT and GMS)	(bas	2001-2003 <sup>2</sup> * ed on DSM-IV crit	eria)
Age group	Total	Male	Female	Total
50-54		0.1%	0.1%	0.1%
55-59		0.0%	0.1%	0.1%
60-64	0.8%	0.3%	0.6%	0.4%
65-69	4.00/	1.2%	1.1%	1.2%
70-74	4.0%	1.8%	1.9%	1.8%
75-79	0.20/	3.1%	3.2%	3.3%
80-84	9.2%	8.0%	8.8%	8.4%
85+	32.2%	12.3%	18.6%	16.4%
<b>50+</b> <sup>§</sup>		1.1%	1.4%	1.3%
60+	5.2%			

<sup>\*</sup> Rates were adjusted for race.

Data sources: <sup>1</sup>Chiam et al. (2004); <sup>2</sup>Sahadevan et al. (2008)

<sup>§</sup> Rates were adjusted for age.

#### 3.4 Summary

Based on clinical diagnoses, two previous prevalence studies in Hong Kong showed an increasing trend in dementia prevalence from 1995 to 2005-2006. About one in three (32%) community-dwelling people aged 85 and above in Hong Kong had dementia in 2005-2006. We projected that the number of community-dwelling people aged 60 and above with dementia would more than double from 0.09 million in 2010 to 0.23 million in 2036, of whom over 30% are aged 85 and above. People with dementia also represent a large proportion of those living in institutional care. A study of the prevalence of dementia found that the prevalence rate of clinically diagnosed dementia among people aged 70 and above living in institutions was 17.4% in 1995. We also projected that the number of people aged 60 and above living in institutions with dementia would increase from 0.02 million in 2010 to 0.05 million in 2036.

The prevalence rates of clinically diagnosed dementia reported in the two previous prevalence studies in Hong Kong were comparable with the rates in Japan, but were higher than those reported in China and Singapore and lower than those reported in the United States. Discrepancy between studies may be due to the difference in age structure, the number of subjects living in institutions, vascular risk profile, and diagnostic criteria of dementia.





## Chapter 4

# Trends in Dementia Incidence in Hong Kong



### Trends in Dementia Incidence in Hong Kong

Cohort studies are particularly valuable for less-biased investigation of disease occurrence and essential for health care planning. These studies start with a group of older people who do not have dementia, and follow them over time to measure the incidence rates. However, there is a paucity of data related to incidence of dementia in Hong Kong and only one unpublished study has been carried out. This chapter reviews the incidence of dementia in Hong Kong. Attempts were also made to compare incidence rates in Hong Kong with those reported in other countries.

#### 4.1 Previous estimates of dementia incidence

A cohort study of elderly Chinese aged 70 and above living in the community and in institutions was carried out in Hong Kong in the 1990s (Ho *et al.*, unpublished data). It was found that the incidence rate of self-reported doctor diagnosis of dementia was 7.9 per 1,000 in a 36-month follow-up period. This works out to an annual incidence rate of 2.6 per 1,000 population or 2.8 per 1,000 person-years. Like the prevalence rates of dementia, incidence rates increased with age for both genders, with the rate at 36 months follow-up among those aged 70 to 79 being 4.2 per 1,000 and among those aged 80 and above being 12.8 per 1,000. There was no obvious difference in the incidence rates between males and females aged less than 80, but females aged 80 and above tended to have a higher incidence rate of dementia (18.3 per 1,000) than their male counterparts (6.2 per 1,000) (Table 4.1). These data, however, need to be interpreted with caution because self-reported data may undercount those in whom dementia has not been diagnosed and thus leading to an underestimation of the incidence of dementia.

Table 4.1 Number and rate of self-reported dementia incidence at 36 months follow-up, by age group, 1991-1992

Age group		Male			Female			Total	
	n*	n§	%	n*	n§	%	n*	n§	%
70-79	498	2	0.4	454	2	0.4	952	4	0.4
<del>80</del> +	321	2	0.6	382	7	1.8	703	9	1.3
70+	819	4	0.5	836	9	1.1	1655	13	0.8

<sup>\*</sup> Number of subjects who were normal at baseline

Data source: Ho et al., unpublished data

<sup>§</sup> Number of subjects impaired at 36 months follow-up

#### 4.2 Comparison of incidence with other countries

Comparisons of incidence of dementia across studies are difficult due to differences in sample characteristics, vascular risk profile, and diagnostic criteria of dementia. Therefore, international comparisons can only be conducted in a broad sense. There is scant information on the incidence of dementia in Hong Kong. Results reported from Ho's study (Ho *et al.*, unpublished data) in Hong Kong and those from selected countries including the United States, the United Kingdom, China, and Japan are briefly described in Table 4.2. Incidence estimates based on modelling were not included in the table.

The incidence rates of dementia across countries varied but all consistently show an exponential increase of dementia incidence with age. Hong Kong has a low incidence rate of dementia. This estimate, however, needs to be interpreted with caution because self-reported data may undercount those in whom dementia has not been diagnosed and thus leading to an underestimation of the incidence of dementia. Compared with incidence rates of dementia in other countries (Kawas *et al.*, 2000; Matsui *et al.*, 2009; Meguro *et al.*, 2007; Paykel *et al.*, 1994; Waite *et al.*, 2001), lower incidence rates have been reported from China (Zhang *et al.*, 1998). Details about age-sex-specific incidence rates of dementia in individual countries are presented in subsequent sections.

Table 4.2 Incidence studies of dementia in Hon	a Kong and selected countries
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Year	Location	Sample characteristics	Dementia diagnostic criteria	Age	Annual incidence	Source
1991- 1995	Hong Kong	Elders living in the community and in institutions in a district	Self-reported	70+ 80+	2.8 per 1,000 person-years 5.1 per 1,000 person-years	Ho <i>et al.,</i> unpublished data
1985- 1998	United States	Elders living in the community	DSM-III-R	55+ 65+	16.7 per 1,000 person-years Alzheimer's disease: 16.1 per 1,000 person-years	Kawas <i>et al.</i> (2000)
1985- 1990	United Kingdom	Elders living in the community or in institutions	CAMDEX	75+	43 per 1,000 person-years	Paykel <i>et al.</i> (1994)
1991- 1994	Australia	Elders living in the community in a city	DSM-III-R and DSM-IV	75+	54.2 per 1,000 person-years	Waite <i>et al.</i> (2001)
1987- 1992	China	Elders living in the community in a city	DSM-III	65+	11.5 per 1,000 population	Zhang <i>et al.</i> (1998)
1985- 2002	Japan	Elders living in the community in a town	DSM-III-R	65+	32.3 per 1,000 person-years	Matsui <i>et al.</i> (2009)
1998- 2005	Japan	Elders living in the community in a rural area	DSM-IV and CDR 1+	65+	40.0 per 1,000 person-years	Meguro <i>et al.</i> (2007)

Abbreviation: CAMDEX, Cambridge Mental Disorders of the Elderly Examination; CDR 1+, Clinical Dementia Rating of 1 and above; DSM-III-R, Diagnostic and Statistical Manual of Mental Disorders, Third Edition, Revised; DSM-IV, Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition

Recently, Alzheimer's Disease International has attempted to compare the incidence of dementia among Hong Kong and selected Asia-Pacific regions in 2005 (Access Economics, 2006). Controlling for the population size, Japan had the highest incidence rate of dementia in 2005 (4.5 per 1,000 population), followed by Australia (3.0 per 1,000 population) and Hong Kong (2.7 per 1,000 population) (Figure 4.1). It was projected that the incidence of dementia in Hong Kong would increase by 4.4 times from 18,500 new cases per year in 2005 to 99,600 new cases in 2050. By contrast, China will experience a relatively smaller increase over the period. The most rapid growth in dementia incidence is projected for Singapore (8.3 times the number of new cases of dementia in 2050 relative to 2005), while Japan shows the slowest increase in incidence of dementia, although 2.5 times the incidence of 2005 by 2050. The incidence in Australia would more than triple from 2005 to 2050 (Table 4.3) (Access Economics, 2006).

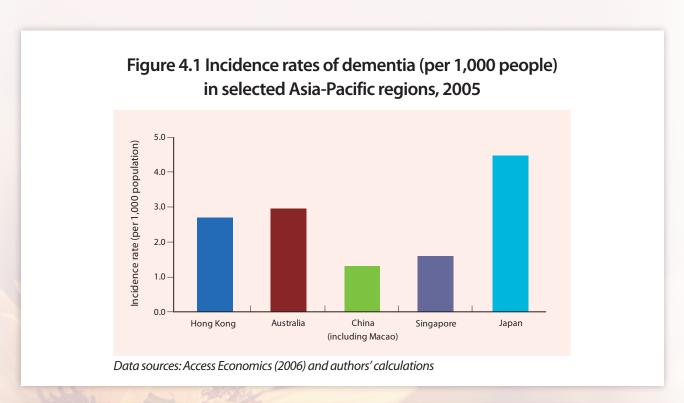


Table 4.3 Incidence of dementia (in thousand) in selected Asia-Pacific regions, 2005-2050

Asia-Pacific region	2005	2020	2050	% change (2005-2050)
Hong Kong	18.5	32.6	99.6	438% increase
Australia	60.2	91.1	199.7	232% increase
China (including Macao)	1,721.0	2,916.7	8,269.0	380% increase
Singapore	6.8	15.7	56.7	734% increase
Japan	570.2	983.4	1,417.7	149% increase

Data source: Access Economics (2006)

#### 4.2.1 United States

In the United States, a 13-year follow-up study of 1,236 people was conducted in 1985-1998 to estimate age-specific incidence rates of dementia (Kawas *et al.*, 2000). Using DSM-III-R criteria, the annual incidence rate of dementia (including Alzheimer's disease, mixed/multi-infarct dementia, Parkinson's with dementia, other dementia, and unspecified dementia) was 16.7 per 1,000 person-years among those aged 55 years and above. The corresponding rate for Alzheimer's disease was 12.3 per 1,000 person-years. The incidence rates increased with age for both genders. For Alzheimer's disease, the incidence rates increased from 0.8 per 1,000 person-years in the 60 to 64 age group to 64.8 per 1,000 person-years in the 85+ age group (Table 4.4). The Framingham Study, which followed the subjects for a maximum of ten years, also showed that dementia incidence rates increased with age, from 7.0 per 1,000 for those aged 65 to 69 to 118.0 per 1,000 for those aged 85 to 89 (Bachman *et al.*, 1993).

Table 4.4 Incidence rates of Alzheimer's disease (per 1,000 person-years) in the United States, by age group and sex, 1985-1998

Age group	Male	Female	Total
55-59	0.0	0.0	0.0
60-64	0.0	2.5	0.8
65-69	0.9	2.2	1.3
70-74	5.5	1.7	4.2
75-79	7.5	11.0	8.9
80-84	12.5	36.1	21.6
85+	72.0	52.7	64.8
55+	11.2	14.3	12.3

Data source: Kawas et al. (2000)

#### 4.2.2 United Kingdom

In the United Kingdom, a 2.4-year follow-up study of 1,195 elderly aged 75 and above, based on the Cambridge Mental Disorders of the Elderly Examination (CAMDEX) interview, showed that the annual incidence rate of dementia was about 43 per 1,000 person-years. The incidence rates increased with age and approximately doubled for every 5 years up to the age group of 85-89. The annual incidence rate of dementia among those aged 85 to 89 (85 per 1,000 person-years) was nearly four times that among those aged 75 to 79 (23 per 1,000 person-years) (Paykel *et al.*, 1994).

#### 4.2.3 Australia

In Australia, a cohort of elderly people aged 75 and above in Sydney was followed for an average of 3.2 years. Using DSM-III-R and DSM-IV criteria, the incidence rate of dementia was 54.2 per 1,000 person-years in 1991-1994. The age-specific incidence rates of dementia increased with age for both genders. Incidence rates were similar for males and females at all age groups (Table 4.5) (Waite *et al.*, 2001). In 2009, Alzheimer's Australia commissioned Access Economics to estimate dementia incidence in Australia. It was projected that the number of new cases of dementia would increase by 4.5 times from 69,600 in 2009 to 385,200 in 2050 (Access Economics, 2009).

Table 4.5 Incidence rates of dementia (per 1,000 person-years) in Australia, by age group and sex, 1991-1994

Age group	Male	Female	Total
75-79	43.7	42.7	43.4
80-84	36.6	53.8	45.7
85-89	135.1	107.7	117.6
90+		250.0	166.7
75+	47.2	61.9	54.2

Data source: Waite et al. (2001)

#### 4.2.4 China

In China, a 3-year follow-up study examining 1,090 elderly aged 60 and above using modified DSM-III criteria was conducted in an urban area of Beijing. The annual incidence rate of moderate and severe dementia was 0.3% in 1986-1989, with vascular dementia being more common (Li *et al.*, 1991). Another study followed 1,970 elderly aged 65 and above in Shanghai for five years. Using DSM-III criteria for the diagnosis of dementia, the annual incidence rate of dementia was 11.5 per 1,000 population in 1987-1992 and Alzheimer's disease accounted for two-thirds of the cases. The annual incidence rate of dementia was slightly higher in females (12.7 per 1,000 population) than males (9.8 per 1,000 population) but did not reach statistical significance (Zhang *et al.*, 1998).

#### 4.2.5 Singapore

Information on incidence of dementia in Singapore is not readily available.

#### 4.2.6 Japan

In Japan, a 17-year follow-up study examining 828 community-dwelling elderly aged 65 and above was conducted in the town of Hisayama. Based on DSM-III-R, the incidence rate of dementia was 32.3 per 1,000 person-years in 1985-2002, with Alzheimer's disease accounting for 45% of the new cases (Matsui *et al.*, 2009). Another study followed 539 elderly (with Clinical Dementia Rating (CDR) 0 or 0.5 at baseline) aged 65 and above in Tajiri for five to seven years. Using DSM-IV and CDR criteria for the diagnosis of dementia, the annual incidence rate of dementia was 40.0 per 1,000 person-years in 1998-2005. The age-specific rates increased steeply with advancing age and reached 67.9 per 1,000 person-years at age 80 and above. The annual incidence rate of dementia was higher in females aged 70 and above than their male counterparts, but the reverse for those aged 65 to 69 (Table 4.6) (Meguro *et al.*, 2007).

Table 4.6 Incidence rates of dementia (per 1,000 person-years) in Tajiri, Japan, by age group and sex, 1998-2005

Age group	Male	Female	Total
65-69	15.7	2.3	9.6
70-79	36.3	47.7	43.9
80+	60.6	72.5	67.9
65+	33.9	44.0	40.0

Data source: Meguro et al. (2007)

#### 4.3 Summary

There is a paucity of data related to incidence of dementia in Hong Kong. Based on self-reported data, a cohort study in 1991-1992 found that there were about 2.6 new cases among 1,000 people aged 70 and above in a year (2.8 per 1,000 person-years). These estimates, however, are probably underestimated and therefore were not comparable with other countries. Based on the estimates by Access Economics (2006), the estimated incidence of dementia from China and Japan are generally higher than those from other countries. This may be due to the difference in age structure, the number of subjects living in institutions, vascular risk profile, environmental factors, and diagnostic criteria of dementia. Nevertheless, the incidence of dementia across countries consistently shows an exponential increase of dementia incidence with age.



## Chapter 5

## Trends in Dementia Mortality in Hong Kong

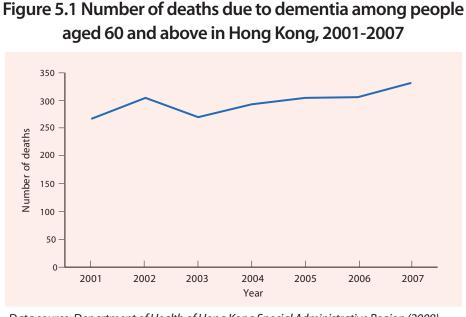


### Trends in Dementia Mortality in Hong Kong

According to the Centre for Health Protection of Hong Kong, dementia (ICD-10: F01-F03) has been the tenth leading cause of death in recent years (Centre for Health Protection, Department of Health of Hong Kong Special Administrative Region, 2010). Before 2001, deaths due to dementia were identified by ICD-9. However, many deaths due to dementia were not coded accordingly in the ICD-9 system (Centre for Health Protection, Department of Health of Hong Kong Special Administrative Region, 2005). Hence, this chapter reviews only trends in dementia mortality in recent years.

#### 5.1 Mortality trends of dementia

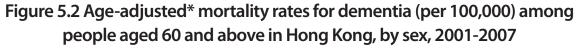
In Hong Kong there were a total of 337 deaths in 2007 (accounting for 0.8% of all deaths) where dementia was the underlying cause (ICD-10: F01, F03, G30, G31) (131 males, 206 females), with 64% of these deaths occurring among people aged 85 years and above (Department of Health of Hong Kong Special Administrative Region, 2008). Among those aged 60 and above, the number of deaths from dementia has been increasing gradually since 2001 (Figure 5.1) (Department of Health of Hong Kong Special Administrative Region, 2008).

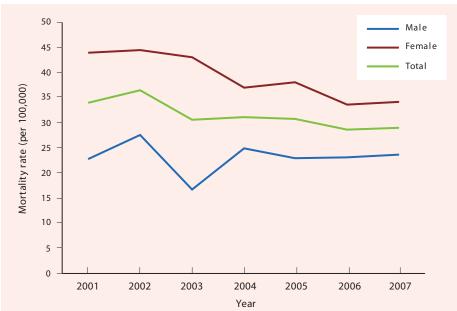


Data source: Department of Health of Hong Kong Special Administrative Region (2008)

The crude mortality rate from dementia increased slightly from 4.1 per 100,000 in 2001 to 4.9 per 100,000 in 2007. However, the age-standardised mortality rate from dementia increased from 2001 to 2002, decreased from 2002 to 2003 and remained stable between 2003 (30.5 per 100,000) and 2007 (29.0 per 100,000) among those aged 60 and above (Figure 5.2).

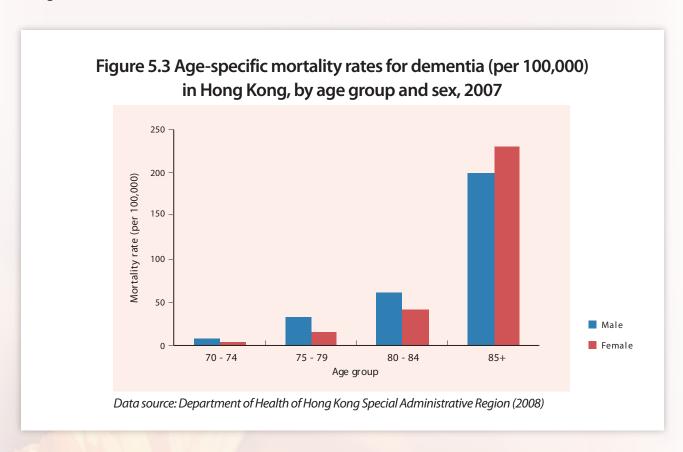
Males and females have different trends in dementia mortality. While the age-standardised mortality rate from dementia followed a decreasing trend in women aged 60 and above between 2001 and 2007, the rate for men decreased from 2002 to 2003, increased from 2003 to 2004 and remained stable between 2004 and 2007 (Figure 5.2) (Department of Health of Hong Kong Special Administrative Region, 2008). Underlying reasons for the differences are not entirely known but is thought to include genetic, environmental, and social factors. Females had a higher mortality rate than males among the older group of 85 years and above. There also exists variation in risk factor between males and females. In addition, more females are surviving to advanced ages, and thus the rate would be higher.





<sup>\*</sup>The age-adjusted mortality rates used the Hong Kong population as of mid-2007 as the standard. Data source: Department of Health of Hong Kong Special Administrative Region (2008)

The mortality rates increased exponentially with age. In 2007, while males aged 70 to 84 had a higher mortality rate from dementia than their female counterparts, the reverse was observed for those aged 85 and above (Figure 5.3) (Department of Health of Hong Kong Special Administrative Region, 2008).

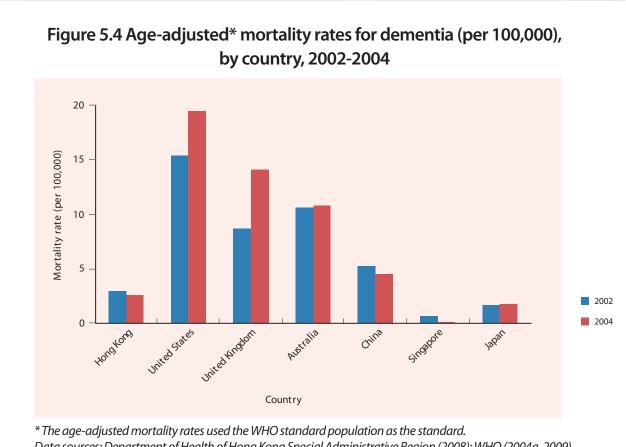


It should be noted that dementia mortality rates are based on underlying cause of death as entered on a death certificate by a physician, and many individuals may have had competing causes of death which were actually complications of dementia. Consequently, some misclassification of reported mortality might occur in individuals with competing causes of death, as well as the possible underreporting of dementia as the cause of death. Hence, we used the attributable risk methodology to estimate the deaths attributable to dementia in order to show the actual burden of dementia. The attributable fraction (AF) is the proportion of cost (e.g. its mortality, disease burden or dollar cost) that can be attributed to a risk factor after controlling for confounding factors. Applying this to the population gives the population attributable fraction (PAF) or the proportion of the cost for the population that is attributable to the risk factor. The PAF is estimated as: PAF = Prevalence  $\times$  (Relative Risk - 1) / [(Prevalence  $\times$  (Relative Risk - 1)) + 1], where prevalence refers to the prevalence rate of dementia in the population of interest and relative risk is the risk of someone with dementia incurring this cost compared with someone without dementia. This PAF is then applied to the total cost for the population of interest.

The relative risk of all-causes mortality among people with dementia compared to those without is 2.38 for people aged 60 to 84, with a smaller relative risk for older ages (Mathers and Leonardi, 2003). We estimated that in Hong Kong, 4,391 deaths among older people in 2006 could be attributed to dementia (that is, a rate of 400.7 per 100,000 population) using the prevalence rates of dementia estimated in Chapter 3.

#### 5.2 Comparison of mortality with other countries

Based on the WHO estimates, Figure 5.4 shows the trends in mortality rates of dementia in Hong Kong and other countries from 2002 to 2004. Standardised to the WHO standard population, it was found that the age-adjusted mortality rate for dementia in Hong Kong was lower than the United States, the United Kingdom, Australia, and China, but higher than Singapore and Japan (WHO, 2004a, 2009). Caution should be exercised when comparing the rate across different countries because many people would have been recorded as dying from another cause which was itself a complication of dementia, and this can contribute to the difference in dementia mortality across studies.



Data sources: Department of Health of Hong Kong Special Administrative Region (2008); WHO (2004a, 2009)

#### 5.2.1 United States

In the United States, the age-standardised mortality rate for Alzheimer's disease (ICD-10: G30) among people aged 65 and above increased by 37% from 128.8 per 100,000 population in 1999 to 176.9 per 100,000 in 2006. The mortality rates increased sharply with age. In 2006, the mortality rate for Alzheimer's disease among those aged 65 to 74 was 20.2 per 100,000 while that among those aged 85 and above was 848.3 per 100,000 (Table 5.1) (National Center for Health Statistics of the United States, 2010).

Table 5.1 Mortality rates for Alzheimer's disease# (per 100,000) in the United States, by age group, 1999-2006

		, -			
Age group	1999	2000	2002	2004	2006
45-64	0.8	0.9	0.8	0.9	1.0
65-74	17.4	18.7	19.7	19.7	20.2
75-84	129.5	139.6	158.1	168.7	175.6
85+	601.3	667.7	752.3	818.8	848.3
65+ (age-adjusted*)	128.8	141.2	158.7	170.6	176.9

<sup>#</sup> ICD-10: G30

#### 5.2.2 United Kingdom

In the United Kingdom, the age-standardised mortality rate for dementia (ICD-10: F01, F03, G30, G31) among the population aged 60 and above increased from 160.3 per 100,000 in 2001 to 177.0 per 100,000 in 2007. The mortality rates increased with age for both genders, and females aged 80 and above tended to have a substantially higher mortality rate than their male counterparts. In 2007, the mortality rates for dementia were 116.4 per 100,000 and 226.3 per 100,000 for males and females, respectively (Table 5.2) (Office for National Statistics of the United Kingdom, 2002-2006, 2008).

<sup>\*</sup>The age-adjusted mortality rates used the U.S. standard population in 2000 as the standard. Data source: National Center for Health Statistics of the United States (2010)

Table 5.2 Mortality rates for dementia# (per 100,000) in England and Wales, by age group and sex, 2001-2007

Age		2001			2003			2005			2007	
group	Male	Female	Total									
60-64	5.5	5.3	5.4	4.6	5.4	5.0	5.2	4.9	5.0	6.1	5.5	5.8
65-69	15.6	11.7	13.6	12.0	13.2	12.6	12.3	11.6	11.9	14.9	13.1	13.9
70-74	40.9	36.3	38.4	41.4	41.7	41.6	37.5	35.8	36.6	39.9	41.1	40.5
75-79	125.0	124.5	124.7	117.5	130.5	124.9	115.0	117.7	116.5	109.0	127.2	119.2
80-84	286.5	319.4	307.2	281.8	344.2	320.7	265.7	336.1	309.1	303.1	363.9	339.9
85+	837.6	1,087.1	1,017.7	848.1	1,214.7	1,110.2	755.1	1,137.5	1,022.5	848.4	1,227.4	1,109.0
60+	108.8	200.3	160.3	107.8	217.7	169.2	102.9	205.7	159.9	116.4	226.3	177.0

# ICD-10: F01, F03, G30, G31

Data source: Office for National Statistics of the United Kingdom (2002-2006, 2008)

#### 5.2.3 Australia

In Australia, the number of deaths from dementia (ICD-10: F01, F03, G30, G31) gradually increased from 3,375 in 1998 to 4,773 in 2005, and then sharply increased in years 2006 (6,719) and 2007 (7,521). The sudden increase might probably be due to an increased tendency for certifiers to identify dementia as a cause of death as reflected by a substantial increase in the number of deaths due to vascular dementia and unspecified dementia (Australian Bureau of Statistics, 2009).

Standardised by age, the mortality rates for dementia (ICD-10: F01, F03, G30, G31) remained stable between 1999 and 2003. The mortality rates from dementia increased sharply with age for both genders, and females aged 80 and above had a higher mortality rate than their male counterparts. In 2003, the mortality rates for dementia among those aged 85 and above were 770.2 per 100,000 and 1,035.7 per 100,000 for males and females, respectively (Table 5.3) (The Australian Institute of Health and Welfare, 2007).

Table 5.3 Mortality rates for dementia<sup>#</sup> (per 100,000) in Australia, by age group and sex, 1999-2003

		,,	- J						
A		1999			2001			2003	
Age group	Male	Female	Total	Male	Female	Total	Male	Female	Total
0-59	0.2	0.2	0.2	0.3	0.2	0.3	0.2	0.3	0.3
60-64	3.1	5.2	4.2	5.6	2.7	4.1	6.6	5.1	5.9
65-69	14.1	11.0	12.5	10.7	9.2	10.0	9.3	10.9	10.1
70-74	42.8	30.9	36.5	34.3	32.6	33.4	29.1	26.1	27.5
75-79	86.7	78.3	81.9	89.7	80.8	84.7	93.9	77.4	84.8
80-84	221.1	246.9	237.1	220.7	225.5	223.6	228.4	250.8	241.9
85+	729.4	908.5	853.9	677.5	958.5	871.7	770.2	1,035.7	952.3
Total (crude)	12.4	24.8	18.6	12.8	26.8	19.8	14.4	29.9	22.2
Total (age-adjusted*)	18.3	20.5	19.9	17.4	20.8	19.8	18.7	22.2	21.1

<sup>#</sup> ICD-10: F01, F03, G30, G31

Data source: The Australian Institute of Health and Welfare (2007)

#### 5.2.4 China

In China, mortality rates for dementia are not readily available. A different measure is presented here for reference. It should be noted that this measure is not comparable to the others presented in this report as this measure only covered dementia patients.

Based on a 40-month follow-up study in Shanghai in 2001, the mortality rate among dementia patients aged 55 and above in a 40-month period was 6.1 per 1,000 person-years. The mortality rates increased with age for both genders and reached 120.5 per 1,000 person-years and 115.9 per 1,000 person-years for males and females aged 90 and above, respectively (Table 5.4) (Hong *et al.*, 2005).

<sup>\*</sup>The age-adjusted rates used the 30 June 2001 Australian population as the standard.

Table 5.4 Mortality rates (per 1,000 person-years) in a 40-month period among dementia patients aged 55 and above in Shanghai, China, by age group and sex, 2001

Age group	Male	Female
55-59	0.0	0.0
60-64	0.9	0.0
65-69	0.0	0.7
70-74	1.0	1.6
75-79	9.8	8.4
80-84	10.3	20.0
85-89	78.9	63.4
90+	120.5	115.9
55 <b>+</b>	5.3	6.6
		<u> </u>

Data source: Hong et al. (2005)

#### 5.2.5 Singapore

Information on mortality of dementia in Singapore is not readily available.

#### **5.2.6 Japan**

In Japan, the mortality rate for dementia (ICD-10: F01, F03, G30, G31) among the population aged 60 and above increased from 11.6 per 100,000 in 1997 to 25.6 per 100,000 in 2008. The agespecific mortality rates also increased sharply with age for both genders. In 2008, the mortality rate for dementia among those aged 60 to 64 years was 2.3 per 100,000 while that among those aged 85 or above was 166.5 per 100,000. Males had higher dementia mortality rates than their female counterparts until the age of 85 (Table 5.5) (Ministry of Health, Labour and Welfare of Japan, 2010).

Table 5.5 Mortality rates for dementia# (per 100,000) in Japan, by age group, 1997-2008

Age		1997			1999			2001			2003			2005			2008	
group	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total	Male	Female	Total
60-64	2.3	1.7	2.0	2.6	1.5	2.0	2.4	1.4	1.9	2.3	1.6	1.9	2.3	1.7	2.0	2.9	1.9	2.3
65-69	3.1	3.0	3.1	3.9	3.3	3.6	4.1	2.9	3.4	4.8	2.6	3.7	4.5	3.1	3.7	5.3	3.7	4.5
70-74	5.8	4.8	5.2	6.4	5.0	5.6	6.9	5.3	6.0	7.4	4.6	5.9	7.1	5.4	6.2	9.6	6.7	8.0
75-79	10.6	8.1	9.0	12.9	9.8	11.0	14.4	10.1	11.8	14.9	9.9	12.0	15.9	11.0	13.1	20.7	14.8	17.3
80-84	27.7	26.0	26.6	26.9	24.8	25.5	31.5	29.1	29.9	31.1	25.2	27.2	30.9	27.0	28.4	47.1	36.8	40.8
85+	77.1	89.7	86.0	85.5	102.6	97.6	96.4	114.9	109.5	101.6	111.8	108.9	102.3	124.3	118.2	144.9	174.6	166.5
60+	9.4	13.3	11.6	10.7	15.4	13.3	12.2	17.7	15.3	13.1	17.5	15.6	13.5	20.6	17.5	19.8	30.2	25.6

# ICD-10: F01, F03, G30, G31

Data source: Ministry of Health, Labour and Welfare of Japan (2010)

#### 5.3 Summary

Dementia is the tenth most common cause of death in Hong Kong. In 2007, 337 people were recorded as dying from dementia. Although the age-standardised mortality rate from dementia among people aged 60 and above remained stable between 2003 (30.5 per 100,000) and 2007 (29.0 per 100,000), the number of deaths from dementia increased gradually among those aged 60 and above during the same period, probably driven by the ageing population. Based on the WHO estimation, the age-standardised mortality rate for dementia in Hong Kong was lower than the United States, the United Kingdom, Australia, and China, but higher than Singapore and Japan in years 2002 and 2004.



## Chapter 6

# Burden of Disability from Dementia in Hong Kong



#### Chapter 6

### Burden of Disability from Dementia in Hong Kong

With the increase in life expectancy, disability associated with dementia has become a common feature in an ageing society. Disability affects the health and quality of life of older people and is associated with a frequent use of health care and social services, thus placing a large burden on patients, caregivers and society. This chapter reviews the relationship between dementia and functional disability in older people and estimates life expectancy at age 60 with and without dementia, and the burden of dementia in Hong Kong in 2010 and 2036.

#### 6.1 Dementia and disability

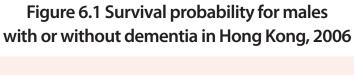
Dementia is a major contributor to disability. In a recent article about the relationship between cognitive function and disability among older people, Kuo et al. (2007) showed that cognitive function was associated with multiple domains of disability, including activities of daily living (ADL), instrumental activities of daily living, leisure and social activities and lower extremity mobility. People with mild cognitive impairment also exhibited higher risk for loss of independent ADL (Greiner et al., 1996), and more gait and balance impairment (Boyle et al., 2007) than cognitively normal people. Several prospective studies also found significant associations between dementia and functional disability as measured by ADL over three to four years (Agüero-Torres et al., 1998; Sauvaget et al., 2002). In a population-based survey of elderly Chinese, ADL dependence was associated with dementia and some other medical conditions (Chen et al., 1995). Occurrence of hip fractures was also elevated among older patients with dementia (Weller and Schatzker, 2004). Plausible explanations for this association have been proposed. Cognitive impairment may affect people's ability to perform motor tasks and consequently reduce muscle strength, resulting in poor physical function and greater risk of falling. Nourhashémi et al. (2002) found that low cognitive function was associated with muscle loss in a group of over 7,000 community-dwelling older women. Rogers and Jarrot (2008) also revealed that cognitive status was a significant predictor of handgrip strength, independent of age and sex. Nevertheless, some studies found that functional decline was the predisposing factor of the development of cognitive impairment and the onset of dementia (Alfaro-Acha et al., 2006; Wang et al., 2006).

As in other Western countries, the population in Hong Kong is ageing rapidly and therefore the increase in prevalence of dementia among the elderly is concerning because, evidence has shown that dementia is associated with increased risk of physical disability. An earlier 18-month follow-up study of elderly Hong Kong Chinese aged 70 and above conducted in 1991-1994 found that dementia was one of the main chronic diseases associated with mild to severe functional limitation (as measured by the Barthel Index) among the subjects (Woo *et al.*, 1998). Auyeung *et al.* (2008) found that poor physical function and muscle strength coexisted with cognitive impairment, independent of muscle mass. Most recently, Tam *et al.* (2008) found that even for older people without dementia, decreased cognitive function was associated with functional impairment. Thus, the high prevalence of cognitive impairment, dementia, and functional disability among older people indicates the need for more focused attention on clinical and public health approaches to reduce this disease and disability burden in this population.

Stigma and social exclusion associated with dementia may also result in excess disability (Sabat, 2009). Previous studies have shown that stigma attached to psychiatric disorders may harm self-esteem (Link *et al.*, 2001) and was associated with a lower sense of psychological well-being and life satisfaction (Markowitz, 1998). Stigma associated with mental illness also prevents people from disclosing their problem and seeking appropriate help (Wahl, 1999), thereby delaying recognition, diagnosis, and treatment. Despite its negative consequences, stigma associated with mental illness has received limited attention. In Hong Kong, a recent survey shows there is likely stigma related to dementia (Department of Health of Hong Kong Special Administrative Region, 2010). The level of health literacy relating to dementia was also low among the lay public as well as health care professionals (Chau and Mak *et al.*, 2010; Department of Health of Hong Kong Special Administrative Region, 2010). Therefore, public education is needed to combat stigma to allow timely recognition and diagnosis of dementia for improving dementia care.

#### 6.2 Life expectancy

Using the Hong Kong Life Tables 2006-2036 (Census and Statistics Department of Hong Kong Special Administrative Region, 2007a) and estimates of the relative risk of mortality from dementia from the GBD study (Mathers and Leonardi, 2003), we estimated life expectancy at age 60 in Hong Kong, with and without dementia. An overseas study showed that the relative risk of mortality in four years among people aged 55 and above with dementia compared to those without was 2.4 (Jagger *et al.*, 2000). Despite people with dementia having a higher risk of dying compared to those without, dementia patients in Hong Kong are expected to live for another 16 years for males and 22 years for females at the age of 60 (Figure 6.1-6.2, Table 6.1).



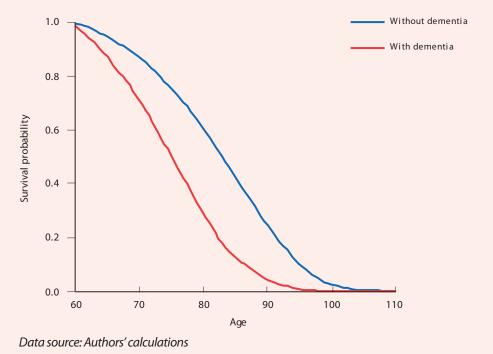


Figure 6.2 Survival probability for females with or without dementia in Hong Kong, 2006

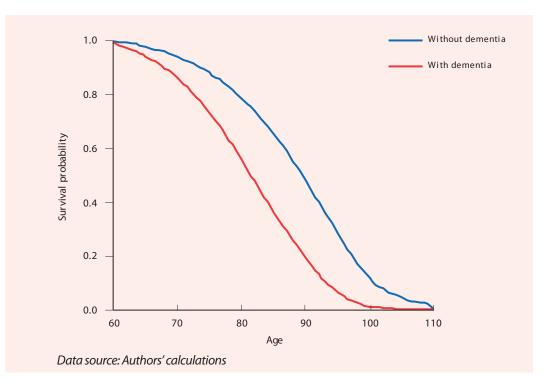


Table 6.1 Life Expectancy at the age of 60 (in years) between people with and without dementia in Hong Kong, by sex, 2006

	General population	Population without dementia	Population with dementia	Difference
Male	22	23	16	7
Female	27	29	22	7

Data source: Authors' calculations

#### 6.3 Estimation of Disability-Adjusted Life Years (DALYs)

Burden of disease is a concept relating to loss of life, health and wellbeing. It can be quantified by Disability-Adjusted Life Years (DALYs) which combine the impact of premature mortality and morbidity. The premature mortality component is measured in terms of years of life lost (YLLs) and the morbidity component in terms of years of life span living in states of less than full health (years lost due to disability, YLDs). The burden of dementia in terms of DALYs has been studied across the world. According to the Dementia in Europe Yearbook 2008, dementia including Alzheimer's disease contributed 2,799,000 DALYs (or 350 DALYs per 100,000 population) in Europe (Alzheimer Europe, 2008). In Australia, an estimate of 101,762 DALYs were lost due to dementia in 2006, and the number was projected to increase to 236,452 in 2031, an increase of over 130%. DALYs lost due to dementia among the population aged 65 and above made up over 90% of DALYs lost to dementia in the Australian population (The Australian Institute of Health and Welfare (AlHW), 2007). The following section presents the methods and results of the estimation of the burden of disease from dementia in Hong Kong.

#### 6.3.1 Years of Life Lost (YLLs)

YLLs are calculated based on the age at which the person dies and the life expectancy for people of that age (as determined by a life table) (Census and Statistics Department of Hong Kong Special Administrative Region, 2007a). In 2006, the 306 deaths among people aged 60 and above where dementia (ICD-10: F01, F03, G30, G31) was the underlying cause of death resulted in almost 2,000 YLLs (Table 6.2). About 58% of these YLLs were for females and 82% were for people over the age of 75.

#### 6.3.2 Years Lost due to Disability (YLDs)

YLDs from dementia are calculated by multiplying the number of people with dementia in Hong Kong by the disability weight that applies to them. It is assumed that all people with dementia in 2006 experienced their condition for the entire year. Based on the Dutch weights from

the GBD study of WHO (Murray and Lopez, 1996; Stouthard *et al.*, 1997), disability weights for mild, moderate and severe dementia are 0.27, 0.63, and 0.94, respectively. Because disability weights for dementia are defined for different levels of severity of dementia, the estimation of YLDs required the average disability weight to be calculated. Based on a local study conducted by Chiu *et al.* (2002) the proportions of mild, moderate and severe dementia were 65.6%, 25.0%, and 9.4%, respectively. Therefore, combined with the disability weights listed above, the average disability weight for dementia is calculated as  $(0.656 \times 0.27) + (0.25 \times 0.63) + (0.094 \times 0.94) = 0.42$ . The YLDs due to dementia is thus calculated by multiplying the number of people with dementia by the disability weight and the life span with dementia. This shows that, overall, there were about 284,000 YLDs due to dementia for people aged 60 and above in 2006.

#### 6.3.3 Disability-Adjusted Life Years (DALYs)

The total burden of disease from dementia, measured in DALYs is the sum of the burden from premature death (YLLs) and the burden of disability (YLDs). In total, about 286,000 years of healthy life were lost due to dementia for people aged 60 and above in Hong Kong in 2006. The majority of burden was due to disability, with YLDs making up 99.3% of DALYs. The remaining 0.7% of the burden was due to the YLLs from dementia (Table 6.2).

Table 6.2 DALYs due to dementia among people aged 60 and above in Hong Kong, by sex, 2006

Aged 60+	Male	Female	Total
YLLs	839	1,148	1,987
YLDs	82,212	202,114	284,326
DALYs	83,051	203,262	286,313

Note: Individual cells may not sum to total due to rounding. Data source: Authors' calculations

#### 6.4 Summary

Dementia is the leading cause of functional disability in older people. However, limited awareness of dementia denies its existence or attaches stigma to the condition, leading to excess disability. The burden of disability associated with dementia is substantial. In 2006, about 286,000 years of healthy life (DALYs) were lost due to dementia in Hong Kong. The majority of the burden was due to disability, with about 284,000 YLDs making up 99.3% of DALYs. The remaining 0.7% of the burden was due to the estimated premature mortality, 2,000 YLLs from dementia.

## Chapter 7

# **Economic Burden from Dementia in Hong Kong**



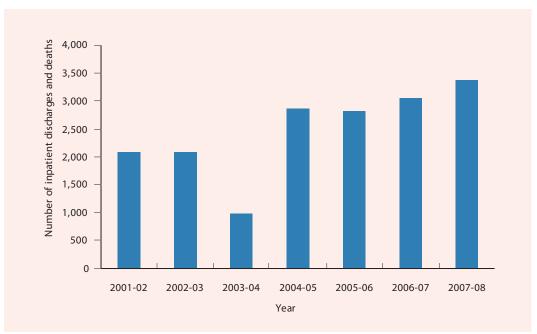
## **Economic Burden from Dementia in Hong Kong**

Because of the increasing number of persons suffering from dementia, costs of care and nursing of people with dementia have an enormous economic impact on the health care and social services systems (Leung *et al.*, 2003). The worldwide cost of dementia was estimated to be US\$ 315.4 billion in 2005, whereas informal care constitutes over one-third of the costs (37%) (Wimo *et al.*, 2007). In Hong Kong, the economic burden of informal care is particularly substantial because the majority of elderly people living in the community receive care from informal caregivers (Chow, 1993). A telephone survey conducted between 2003 and 2004 showed that primary caregivers in Hong Kong had poorer physical and mental health and such caregivers were the major sources of financial support in caring for the elderly (Ho *et al.*, 2007; You *et al.*, 2008). Wimo *et al.* (2007) estimated that the direct costs and informal care costs in Hong Kong totalled US\$ 1.1 to 2.1 billion in 2005. According to Wimo *et al.* (2007), Hong Kong was found to have a similar amount of costs per dementia patient as Japan and Singapore, but higher than China and lower than the United States, the United Kingdom and Australia. This chapter examines the direct and indirect costs of dementia. Examples of direct costs include costs of hospital admissions and institutional care, while costs of informal care are examples of indirect costs.

#### 7.1 Hospitalisation

According to the Hospital Authority statistics, there were 3,050 inpatient discharges and deaths (inpatient episodes) with dementia (ICD-10: F00-F03, G30) as the principal diagnosis, in both public and private hospitals, in Hong Kong in 2006 (98% in public hospitals) (Figure 7.1) (Hospital Authority of Hong Kong Special Administrative Region, 2003-2009). Assuming 78% of these episodes came from those aged 60 and above and the mean bed-day of these episodes was 25 days, we estimated the annual cost of hospitalisation for dementia in people aged 60 and above by multiplying the number of episodes with the mean bed-day and the standard public ward fee per day. The standard public ward fee (i.e. a cost recovery charge) per day was HK\$ 3,300 in 2006 (Special Supplement No. 4 to Gazette No. 13/2003, 2003). It was estimated that the annual cost of hospitalisation for dementia in people aged 60 and above was around HK\$ 197 million (3,050 × 0.776 × 25.3 × \$3,300) in Hong Kong in 2006.

Figure 7.1 Number of inpatient episodes with principle diagnosis of dementia in Hong Kong in both public and private sectors, 2001-2007



Data source: Hospital Authority of Hong Kong Special Administrative Region (2003-2009)

Table 7.1 Estimated cost of hospitalisation for people aged 60 and above with dementia in Hong Kong, 2006

Aged 60+	2006		
Numbers of dementia inpatient episodes in both public and private hospitals	3,050		
Estimated numbers of these episodes that were contributed by people aged 60 and above	2,367		
Estimated mean bed-day of each of these episodes	25		
Cost per inpatient bed-day (HK\$)	3,300		
Estimated cost of hospitalisation (HK\$ million)			

Data source: Authors' calculations

Using the same methodology as in section 3.2, we estimated that in 2006, there were about 90,806 people aged 60 and above with dementia living in both the community and institutional care in Hong Kong. The rate of hospital utilization among dementia patients aged 60 and above was estimated by dividing the number of dementia inpatient episodes contributed by people aged 60 and above by the estimated number of people aged 60 and above with dementia in 2006, i.e.: 26.1 per 1,000 (2,367/90,806).

In section 3.2, we estimated that in 2010, there would be about 105,069 people aged 60 and above in Hong Kong with dementia. Assuming a constant rate of hospital utilization among dementia patients aged 60 and above between 2006 and 2010, the estimated annual cost of dementia inpatient episodes among people aged 60 and above would be around HK\$ 228 million in 2010 (Table 7.2). Using the same methodology and assuming that the rates remain the same, by 2036, the annual cost for hospitalisation would be expected to more than double to HK\$ 594 million (Table 7.2).

Table 7.2 Estimated cost of hospitalisation for people aged 60 and above
with dementia in Hong Kong, 2010 and 2036

Aged 60+	2010	2036
Projected number of people with dementia	105,069	273,449
Estimated number of dementia inpatient episodes (Projected number of people with dementia $\times$ rate of hospital utilization)	2,739	7,128
Estimated mean bed-days of each of these episodes	25	25
Cost per inpatient bed-day (HK\$)	3,300	3,300
Estimated cost of hospitalisation per year (HK\$ million)	228	594

Data source: Authors' calculations

These estimates, however, need to be interpreted with caution because episodes related to complications of dementia, e.g. pneumonia, were not coded under dementia and thus leading to underestimation of the cost of hospitalisation of dementia. In addition, the above estimates were conservative estimate only.

Hence, we used the attributable risk methodology to estimate the hospitalisation costs attributable to dementia in order to show the actual burden of dementia. The attributable cost of hospitalisation was estimated using (i) the number of inpatient episodes for all causes of admission in 2006 being 531,819 (Hospital Authority of Hong Kong Special Administrative Region, 2008), (ii) age-sex-specific prevalence rates of dementia as presented in Chapter 3, (iii) relative risk of hospitalisation associated with dementia being 3.68 (Bynum *et al.*, 2004), (iv) an average bed-days of 8 days per stay (not disease specific), and (v) a unit cost of an inpatient bed-day based on the charge for non-eligible persons in Hong Kong being HK\$ 3,300 (Special Supplement No. 4 to Gazette No. 13/2003, 2003). The attributable cost of hospitalisation for dementia among people aged 60 and above was estimated to be around HK\$ 2.5 billion in 2006. It is estimated that the attributable cost of hospitalisation for dementia among people aged 60 and above would be around HK\$ 2.9 billion in 2010. By 2036, it would be expected to increase to HK\$ 7.6 billion.

#### 7.2 Institutional care

#### 7.2.1 Government subsidised institutional care places

In section 3.2, we estimated that in 2010, there would be about 18,666 people aged 60 and above living in institutional care in Hong Kong with dementia. Based on statistics provided by the Social Welfare Department (SWD), about 32% of institutional places were subsidised by the Hong Kong government in 2010 (Social Welfare Department of Hong Kong Special Administrative Region, 2010). Therefore, it was estimated that 6,036 people with dementia would be living in government subsidised places in Hong Kong in 2010.

Based on the report published by the Audit Commission of Hong Kong (2002), the estimated average government subsidies for providing residence services for the elderly in 2001 was about HK\$ 97,311 per place per year (HK\$ 2,417.6 million / 24,844 places). Based on the SWD figures, the average charge for a subsidised place each month paid by the elderly or their family caregivers was approximately HK\$ 1,755 (or HK\$ 21,060 per year) in 2010 (SWD, 2010). Hence, the cost for a government subsidised institutional care place was taken as HK\$ 118,371 (=HK\$ 97, 311 + HK\$ 21,060) per year.

We estimated that the costs of government subsidised institutional care for people aged 60 and above with dementia would be around HK\$ 714 million in 2010 (Table 7.3). Assuming a constant percentage of government subsidised places among all institutional places between 2010 and 2036, using the same methodology, by 2036, cost of government subsidised institutional care for people aged 60 and above with dementia would increase to around HK\$ 1,853 million (Table 7.3).

Table 7.3 Estimated cost of government subsidised institutional care
for people aged 60 and above with dementia in Hong Kong, 2010 and 2036

Aged 60+	2010	2036
Projected number of people with dementia in institutional care	18,666	48,417
Proportion of government subsidised places among all institutional places	32.3%	32.3%
Projected number of people with dementia living in government subsidised places	6,036	15,655
Costs per place per year (HK\$ million)	0.118	0.118
Estimated annual cost of government subsidised institutional care for dementia patients aged 60 and above (HK\$ million)	714	1,853

Data source: Authors' calculations

#### 7.2.2 Private institutional care places

Since about two-thirds of institutional care places were not subsidised by government, we estimated that 12,631 and 32,762 people aged 60 and above with dementia would be living in places not subsidised by government in Hong Kong in 2010 and 2036, respectively. Although places not subsidised by government include private homes and institutions run by non-governmental organisations, for simplicity, we used private institutional care places to describe both categories. Based on a survey conducted by the Consumer Council, the average charges for a private institutional care place was around HK\$ 6,000 per month (Consumer Council, 2006). We estimated that the costs of private institutional care for people aged 60 and above with dementia would be around HK\$ 909 million in 2010. Assuming a constant percentage of private institutional care places among all institutional places between 2010 and 2036, using the same methodology, by 2036, cost of private institutional care for people aged 60 and above with dementia would increase to around HK\$ 2,359 million (Table 7.4).

Table 7.4 Estimated cost of private institutional care for people
aged 60 and above with dementia in Hong Kong, 2010 and 2036

Aged 60+	2010	2036
Projected number of people with dementia living in private institutional care	12,631	32,762
Average charges for a place at private institutional care unit per year (HK\$ million)	0.072	0.072
Estimated annual cost of private institutional care (HK\$ million)	909	2,359

Data source: Authors' calculations

#### 7.2.3 Estimated total cost of institutional care

We estimated the total cost of institutional care for patients aged 60 and above with dementia by totalling the costs for government subsidised institutional care places and the costs for private institutional care places. It was estimated that in 2010, the annual cost of institutional care in people aged 60 and above was around HK\$ 1,624 million. By 2036, it would increase to around HK\$ 4,212 million. Nevertheless, these estimates have not taken into account subsidies from the non-governmental organisations.

#### 7.3 Informal care

Most people with dementia receive care at home initially, with day-to-day personal needs supported by family caregivers. Therefore, the cost of informal care for dementia is one of the main burdens to society. Costing informal care and unpaid work is indeed a controversial and complicated issue, and several methods have been proposed. Informal care should be valued by the opportunity cost of the caregivers' time; however, identifying this opportunity cost is not straightforward.

We estimated the cost of informal care by valuing the alternative paid employments of the time spent on caring. Using a median wage from main employment of HK\$ 10,000 per month in 2006 as reference (Census and Statistics Department of Hong Kong Special Administrative Region, 2007c), it was estimated that the opportunity cost of this informal care for people aged 60 and above with dementia was around HK\$ 10,368 million in 2010. By 2036, this would increase to HK\$ 27,004 million.

Table 7.5 Estimated cost of informal care for people aged 60 and above
with dementia in Hong Kong, 2010 and 2036

Aged 60+	2010	2036
Projected number of people with dementia living in the community	86,402	225,032
Median monthly income from main employment (HK\$)	10,000	10,000
Estimated cost of informal care per year (HK\$ million)	10,368	27,004

Data source: Authors' calculations

#### 7.4 Summary

Institutional care and informal care are the major components for costs of dementia. In 2010, the cost of institutional care resulting from dementia in people aged 60 and above is estimated at around HK\$ 1,624 million, based on a prevalence estimate of 105,069 people with dementia in Hong Kong in 2010. By 2036, the cost of institutional care would increase by 1.6 times to around HK\$ 4,212 million per year. Costs of informal care are also projected to increase as the prevalence of dementia grows. Costs of informal care were estimated to be around HK\$ 10,368 million in 2010 and would increase to HK\$ 27,004 million by 2036. These estimates only include part of the costs involved in caring for dementia patients.



### Chapter 8

# Implications and Recommendations for Hong Kong



## Implications and Recommendations for Hong Kong

#### 8.1 Awareness and stigma

There is a prevalent view among health and social care professionals as well as the lay public that dementia is an inevitable normal accompaniment of ageing, instead of a chronic disease which patients ultimately die from. There is lack of awareness that dementia makes the largest contribution to disability in China and other developing countries (Sousa *et al.*, 2009). In addition, it is not widely appreciated that poor physical function and muscle strength often co-exist with cognitive impairment (Auyeung *et al.*, 2008).

Furthermore there is anecdotal evidence of social concealment of the condition, which appears to carry some degree of stigma, resulting in social exclusion. Studies in other countries have documented reduced social contact after diagnosis, and different social interactions with friends and relatives (Werner and Heinik, 2008). Stigma may create a barrier between dementia sufferers and various medical and psychosocial interventions. Excess disability can be created as a result of how patients are treated by others (Sabat, 2009).

Recent surveys of lay public as well as health care professionals show that the level of health literacy relating to dementia is low (Chau and Mak *et al.*, 2010; Department of Health of Hong Kong Special Administrative Region, 2010). Therefore public education and training of health care professionals are both needed in raising awareness of the disease and its management. In particular there is a need to educate all on how to communicate with those who have dementia.

#### 8.2 Prevention and early detection

Although few risk factors have been identified for Alzheimer's disease, which accounts for approximately 65% of dementia in Hong Kong (Chiu *et al.*, 1998), about one-third is caused by underlying cardiovascular disease resulting in stroke. There is evidence that a 'healthy lifestyle' is associated with a slower decline in cognitive function in large-scale prospective studies. A population-based study of more than 1,400 people showed that high age, low education, hypertension, hypercholesterolaemia, and obesity were associated with increased risk of dementia

20 years later (Kivipelto *et al.*, 2006). Therefore there is room for prevention or reduction of vascular dementia by modifying lifestyle: avoidance of smoking, alcohol in moderation, a diet rich in fruits, vegetables and fish but low in saturated fats, maintenance of optimal body weight, and regular physical activity. Detection and effective treatment of hypertension are also important. A scoring system for the prediction of the risk of late-life dementia in people of middle age on the basis of their risk profiles has been developed (Kivipelto *et al.*, 2006). It has been estimated that delaying the onset of dementia by two years could lead to a 20% reduction in Alzheimer's disease prevalence while a 5-year delay could result in a 50% reduction (Brookmeyer *et al.*, 1998).

Currently diagnosis tends to be made at a later stage of the disease, with up to 90% of people with mild dementia being undetected in the primary care setting. Cognitive function should be a regular feature of health assessment in the elderly in primary care, whether carried out by the family physician or a team of health professionals as part of a comprehensive geriatric assessment in community centres. Cognitive assessment is even more important in the hospital setting, as the majority of patients are elderly, especially in the medical wards. Management of multiple morbidities must take into account the presence or absence of cognitive impairment to be comprehensive.

Since assessment takes time, and doctors have limited time in hospitals as well as in clinics, the setting up of assessment teams by trained healthcare workers would be a solution, so that doctor consultation time is maximised to enable investigations and care plans to be formulated based on the report of assessment forms. Such a system has been in practice for primary care geriatricians' practices in the community in the United States.

#### 8.3 Care and support for patients and their caregivers

Management of the disease includes optimizing physical health and cognition through lifestyle modification and cognitive exercises; detecting and treating behavioural and psychological symptoms of dementia (BPSD); providing information and long term support to caregivers. The use of cholinesterase inhibitors and/or other psychotropic drugs may be indicated, but should not be regarded as the mainstay of treatment. Other than pharmacological intervention, other modalities should include personal, cognitive and social rehabilitation. Empowerment of formal and informal caregivers through education, social support and counselling is needed to enhance their interactions with people with dementia, so that excess disability is kept to a minimum and quality of life is maximised (Sabat, 2009).

Dementia care would best be delivered by a multidisciplinary team in the primary care setting, where continuity of care is possible, supported by psycho-geriatricians and geriatricians in secondary or tertiary care settings. In this regard the primary care setting in Hong Kong is not supportive of elderly people with dementia, who often have multi-morbidities, in that few clinics have multi-disciplinary teams to carry out detailed assessments. Even in hospital settings, other than patients under geriatric teams, those not under their care may not receive optimal care.

In 1999-2000, Dementia Day Care in the community as well as Dementia Care units in institutional care homes for the elderly were piloted in the subvented sector as a result of a government commissioned consultancy. One centre was established by the Hong Kong Jockey Club Charities Trust to run on a self-sustaining basis. The latter is now entirely self-sustaining, showing that this model of care is feasible other than government subvention. Day care programmes have been shown to reduce BPSD, caregiver stress, and the rate of functional decline. The use of telemedicine may also have a role in the delivery of group cognitive training programmes in such centres, by a professional in a remote site (Poon *et al.*, 2005). A recent study in Hong Kong showed that cognitive impairment, including dementia, is one of the main factors predisposing to admission to long term institutional care (Woo *et al.*, 2000). Improved support at the community level may delay admission, as suggested by a past survey (Chiu, unpublished data). Studies in Finland (Eloniemi-Sulkava *et al.*, 2001) and the United States (Gaugler *et al.*, 2005) also found that offering community-based support delayed admission into institutional care. Demand for such services is likely to increase as a result of the impact of population ageing.

Informal caregivers would need to be an integral part of care, however, the oldest old support ratio has been decreasing in other countries as well as in Hong Kong (Chau *et al.*, 2007; Robine *et al.*, 2007). A recent Hong Kong survey has shown that primary informal caregivers have worse health, more doctor visits, anxiety and depression, and weight loss compared with non-caregivers, and that all domains of health-related quality of life were adversely affected. Poorer physical and psychological outcomes were correlated with caregiver burden as measured by the Zarit Burden Scale (Ho *et al.*, 2009). A telephone survey has also found that patients with dementia who get lost in the community put a considerable psychological strain on their caregivers (Kwok *et al.*, 2010). Support for caregivers of dementia patients would need to be improved, to include both practical as well as psychological support. These may include caregiver education covering communication and caring skills for dementia patients, and the application of principles of bereavement used in palliative care, since there are similarities in the gradual loss of personhood of the family member

such that the caregiver may be treated as a stranger. There is evidence that enhanced counselling and support treatment may reduce caregiver's depression (Mittelman *et al.*, 2004). Collaborative care packages including education on communication skills, caregiver coping skills, legal and financial advice, patient exercise guidelines, and caregiver guide may also improve quality of care and behavioural and psychological symptoms of dementia for both people with dementia and their caregivers (Callahan *et al.*, 2006). Easily accessible day and respite care would also be important.

#### 8.4 Long term institutional care

In the latter stages of dementia, when the patient becomes immobile, cannot swallow, and is doubly incontinent, institutional care may not be avoided. Cognitive impairment, including dementia, is one of the major factors influencing caregivers to opt for the choice of institutional care (Chau and Kwok *et al.*, 2010). There are issues of quality of care, autonomy and dignity that need to be addressed. Intermittent reports in the media in the past two decades have highlighted undesirable practices amounting to abuse. Quality of care depends to a large extent on adequate staff numbers (Woo *et al.*, 2005). The number of staff required for an institution depends on the dependency level of the residents, and the number required for an acceptable quality of care depending on case mix can be estimated in a simple way (Woo and Chau, 2009). Using this method, staff numbers in many institutions, particularly privately run ones, are not sufficient. It is recognized that there is a tension between quality and affordability, and this is unlikely to be resolved until the financing of long term care is addressed.

#### 8.5 End of life care

There is a lack of awareness that dementia is a terminal illness, so that many people with advanced dementia do not receive palliative care. A study in the nursing home setting in the United States showed that compared to residents with cancer, those with dementia tend to have more non-palliative interventions (5% versus 25% tube fed), have inadequate symptom treatment, and fewer have advanced care planning (Mitchell *et al.*, 2004). The 6-month mortality is 25% and 18-month mortality is 55% in a recent survey of nursing home residents with advanced dementia (Mitchell *et al.*, 2009). These figures are comparable to those for more aggressive cancers. Pneumonia, febrile episodes and eating problems were common, as were distressing symptoms of dyspnea and pain. In spite of the terminal nature of the disease, burdensome interventions such as hospitalisation, emergency room visits, parenteral therapy and tube feeding occurred in 41% of such cases.

A survey in a non-acute hospital in Hong Kong revealed similar practices (Lee and Woo, 2008). During a 3-month period, 28 patients died of end-stage dementia, with a mean age of 88 years. About 82% were from institutional care. Their acute and convalescence hospital stays lasted for an average of 9.3 and 35.9 days respectively. The mean waiting time in accident and emergency department before admission was 140 minutes. During their last hospitalisation (acute and convalescent), a mean of 44 laboratory specimens were collected and 4.2 imaging tests were performed. During their last stay in the convalescence hospital, the end-stage dementia patients were kept nil by mouth for a mean of 3.3 days, were put on intravenous / subcutaneous fluids for 11.4 days and had taken antibiotics for 11.5 days. All these patients were incontinent and dysphagic, 79% were tube-fed and 57% were on a urinary catheter. The median Norton score was 9/20: 75% suffered at least one pressure ulcer and 7% had gangrenous limbs. About 20% had their arms restrained to prevent them from pulling off tubes and lines. About 82% were mute and the maximum AMT score among the rest was only 3. While half of these patients died of pneumonia and 18% died of bedsore or gangrene sepsis, dementia was never labelled as the principle diagnosis in the record and was labelled as a secondary diagnosis in only 29%.

It has been pointed out that palliative and hospice care could greatly improve the care of patients with advanced dementia resulting in better quality of life and greater caregiver satisfaction, at the same time reducing hospitalisation (Sachs, 2009). There is a need to raise awareness and improve the quality of care for such patients. A quality improvement initiative for such patients at the end of life has been developed and evaluated in a non-acute hospital, and integrated into part of the care plan (Woo and Lo *et al.*, 2009).

#### 8.6 Legal and financial issues

Raising awareness of the use of the power of attorney for decisions regarding care plans as well as asset management is important, and may help reduce physical and financial abuse of those with dementia. Such services and advice should be easily accessible and user friendly.

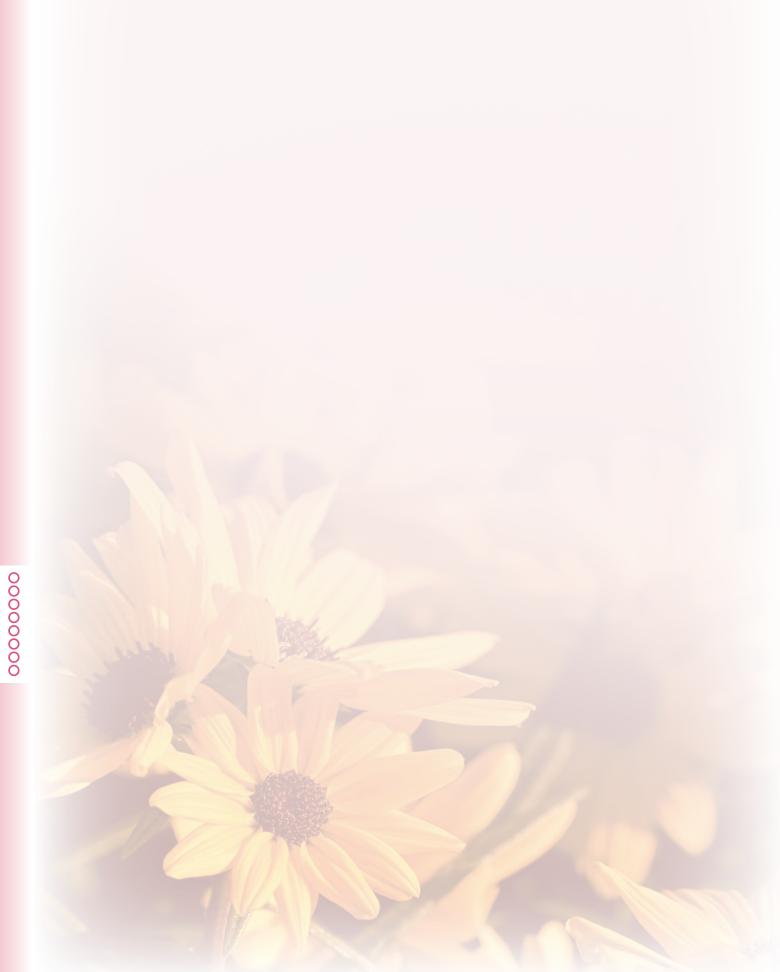
The costs of care for patients with dementia can be considerable, covering expensive drugs as well as payment for long term social and medical care. It is likely that the financing of care for people with dementia would involve co-payment in addition to government provided resources. Perhaps such issues could be highlighted and debated so that a realistic strategy can be formulated. In this regard, societal ageist attitudes may be uncovered that indicate lower priorities be accorded to such patients where there are resource limitations.

#### 8.7 Future research and service development

A research database covering various aspects of dementia in Hong Kong (such as epidemiology, pharmacological treatments, patients' and caregivers' needs, different modes of service delivery and evaluation, cost effectiveness) would be useful so that gaps in knowledge could be identified. Such information would be necessary to enable the development of a dementia strategy for Hong Kong.

The CADENZA Project, a Jockey Club Initiative for Seniors, being a collaborative effort between the Hong Kong Jockey Club Charities Trust, the Faculty of Social Sciences of The University of Hong Kong, and the Faculty of Medicine of The Chinese University of Hong Kong, has been addressing some of the areas listed above. Supported by the Project, a public survey revealed poor knowledge relating to the care of people with dementia (Chau and Mak *et al.*, 2010). The Project also supported training of professionals and the lay public regarding elderly issues including dementia care (CADENZA, 2009a), supported a quality improvement initiative for end of life care in a non-acute hospital (Woo and Lo *et al.*, 2009), supported a study on the needs of caregivers and elderly people who require care with an emphasis on dementia (Chau and Kwok *et al.*, 2010) and initiated an integrated social-medical care model in the community where those with cognitive impairment may receive various services (CADENZA, 2009b).





## Chapter 9

## Conclusion



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#### Conclusion

Almost 91,000 people aged 60 and above had dementia in Hong Kong in 2006, and over 105,000 in 2010. With the ageing population, the number of cases of dementia is expected to increase to about 273,000 by 2036. Dementia contributes significantly to disability and about 286,000 years of healthy life were lost due to dementia in Hong Kong in 2006. The majority of the burden caused by dementia was due to disability rather than premature death, with disability accounting for 99.3% of the total disease burden. Costs for dementia are enormous, and institutional care and informal care constitute the major components for financial costs of dementia. By 2036, the annual costs of institutional care would increase to around HK\$ 4,212 million, whilst the annual costs of informal care were projected to be HK\$ 27,004 million. With the publication of this report highlighting the impact of dementia on an ageing population, it is hoped that public awareness could be raised and a strategy developed to improve the quality of life and quality of care for those with dementia. Therefore, formulation of a dementia care strategy as part of a care of the elderly strategy would be important for Hong Kong, in view of the magnitude of the dementia burden.





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