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COST OF INFORMAL CARE OF DEMENTIA IN SINGAPORE

A DISSERTATION

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THE REQUIREMENTS

FOR THE DEGREE

DOCTOR OF PHILOSOPHY

(HEALTHCARE SCIENCES)

BY

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B.A, M.SOC.SCI. (ECONOMICS)

APRIL 2016

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STATEMENT ON THE CONTRIBUTION OF OTHERS

I recognize the Memory Ageing and Cognition Centre at National University of Singapore and the Institute of Mental Health, Singapore, for granting me the approvals for the onsite study.

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I also recognize the JCU Ethics Committee for ensuring that all research conducted for this thesis met ethical standards and received approval.

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DECLARATION ON ETHICS

The research presented and reported in this thesis was conducted within the guidelines for research ethics in the National Statement on Ethics Conduct in Research Involving Humans (1999), and the James Cook University Statement and Guidelines on Research Practice (2001). The proposed research methodology received clearance from the James Cook University Ethics Review Committee (H5140, Category 3). Approval Number: H5140

The proposed research study also received approvals from the Clinical Research Committee (CRC) at The Institute of Mental Health, Singapore (CRC Ref No: 473-2014) and The National Healthcare Group Domain-Specific Review Board, Singapore (DSRB Reference Number: 2015/00220).

Lai Leng Woo

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GOD: Glory to GOD for giving me this opportunity to complete my academic journey. Philippians 1: 6

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ABSTRACT

Background: Informal costs of care including caregiver and foreign domestic workers (FDWs) time are important components of total cost of care for patients with dementia (PWD) and should be considered alongside formal costs such as medication and health service use. This study quantified the informal caregiver time and formal cost of medication and health service use for PWDs in Singapore and compare with those people without dementia (PWODs).

Methods: This study recruited 137 (with no dementia) and 51 patient- caregiver dyads with mild, moderate and severe dementia. The Resource Utilization in Dementia (RUD) instrument is used to quantify informal caregiver time and medication and health service use. The Barthel Index and the Subjective level of function are used to measure functional capabilities. The Chinese Mini Mental State Examination is used to measure the stage of dementia. The opportunity and replacement cost methods are used to calculate the wages forgone in terms of time for the caregivers of PWDs and PWODs.

Results: Comparisons of this study results for PWD and PWD are summarised below.

***Age and Gender*:** The mean age of the caregiver for PWOD was older at 61.65 (*SD* = 12.45) compared to those PWD at 53.24 years (*SD* = 14.22). Females were the majority caregivers for PWDs and PWODs.

Relationship to patients: Spouses were the main caregiver for PWODs while children were the main caregivers for those PWDs. A few FDWs (1.96%) were the primary caregivers for PWDs but there was none for those PWODs.

Employment Status: A third (33.58%) of the caregivers for PWODs was gainfully employed while about half of the caregivers for PWDs were gainfully employed.

Living Accommodation: Majority of these PWODs (83.21%) stayed at home with their families and lived in their own homes (96.67%). But only slightly more than half of PWDs (54.90%) stayed with their families and less than half of them (47.06%) actually lived in their own homes.

Other caregivers: More than half of the caregivers (51.09%) were sole caregivers in taking care of PWODs while almost half (49.10%) of the primary caregivers had one other caregiver in helping them to take for PWDs.

Level of contribution by primary caregiver: Less than a third (28.47%) the primary caregiver spent 21-40% of their time in taking care of PWODs, while a third (33.33%) of the primary caregivers spent 1-20% of their time in caring for PWDs.

Presence of FDWs: A few primary caregivers employed FDWs (14.60%) in their households for PWODs. These FDWs were mainly to do housekeeping chores for these families. However, more than half of the households (58.82%) had employed FDWs for PWDs.

ADL, IADL and Supervision: The time spent by caregivers on ADL, IADL and supervision for PWODs were much lesser compared to those PWDs. This was mainly because these PWODs had lesser problems in their daily activities and hence also required less supervision compared to those with dementia.

Informal cost of care: The mean annual informal cost of care for PWODs was SG$ 5,477.03 while those PWDs was SG$ 44,530.55. Informal care costs were highest for patients with severe dementia, compared with patients with mild or moderate dementia. The mean annual informal cost of care was higher (*M* = SG$44,530.55, *SD* = 31,354.82) compared to the mean annual formal cost of care in Singapore (*M* = SG$25,654.11, *SD* = 10,016.48).

Conclusion: The study main findings were: 1) the mean annual cost of informal care for PWDs in Singapore was 1.7 times higher than cost of formal care; 2) the mean annual informal cost of care was 2.3 times higher than full time cost in Residential Care Facilities (RCFs); 3) the formal cost of care was highest for PWDs in RCFs, DCCs (Day Care Centres) and the direct medical cost (dementia); 4) informal cost of care for PWDs was the highest (63%), followed by direct social costs (33%) and direct medical cost (includes dementia and non-dementia medications (4%); 5) the annual costs of informal care for dementia care increased with disease severity; 6) for each higher value of CMMSE, the informal cost of care is reduced by SG$1,173.94; 7) there was no significant association between annual cost of informal care and functional abilities; 8) the mean annual informal cost of care in Singapore is comparable with those in developed countries like the United States, United Kingdom and Japan; 9) the informal cost of care for those with dementia did not vary much with or without the use of DCCs or DDCCs; 10) the costs for those who did not have FDWs was approximately more than double the costs for those with FDWs; 11) PWDs also suffered from an average of five other chronic health conditions; 12) the most common chronic conditions reported by these PWDs were hypertension, hyperlipidaemia, diabetes mellitus and ischemic heart disease; 13) the most commonly reported medications for patients with other chronic conditions included antipsychotics agents, antihypertensive agents and medications for dyslipidemia; 14) about three-fifths of PWDs had FDWs compared to less than a fifth of those PWODs; 15) the mean annual informal cost of care for PWODs was SG$ 5,477.03 while those PWDs was SG$ 44,530.55; and 16) the cost of a screening programmes in polyclinics for all PWDs was SG$64,800 (one-time) or estimated SG$518,400 to employ 18 nurses once a year or SG$547,200 if one extra nurse is employed

The number of PWDs is rising rapidly worldwide due to higher life expectancy. Singapore is no exception with a rapidly ageing population and these ageing caregivers also have their own health care problems. There are currently about 40,000 people with dementia in Singapore (Alzheimer's Disease Association, Singapore, 2016), which is costing the government SG$2.81 billion annually. By 2030, that number is expected to rise to 92,000 (Alzheimer's Disease Association, Singapore, 2016). This will cost the government healthcare expenditure to escalate almost triple to SG$ 6.46 billion, of which SG$4.10 billion will be attributable to informal cost of care and SG$2.36 billion to formal cost of care for PWDs in Singapore.

In the long term, the informal cost of care in Singapore is likely to be shifted to the formal cost of full time RCFs when the cognition and function of the patients with dementia deteriorates further. Thus the cost will be transferred from caregivers to society. Transition from full HC or partial HC and DCCs or DDCCs into RCFs will only increase total costs of dementia care from a societal perspective. Ultimately, this is simply a zero sum game, where nobody benefits.

Further Research: Going forward, further research on a broadly defined framework to possibly include policies implementation into education and awareness campaigns, subsidy for dementia medications, more funding mechanisms for enrolment into DDCCs, DCCs, and RCFs, better integration of care management and services, expanding specialty services, more centralised screening and diagnostic facilities and memory clinics island-wide, improved training for health care professionals and caregivers and families, benefits and rewards scheme for informal caregivers and strengthening and expanding of the existing infrastructure for quality health care services for PWDs.

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CHAPTER

LIST OF ABBREVIATIONS

This section will provide a list of abbreviations that will be used in this thesis.

ADL	Activities of Daily Living
CI	Cognitive Impairment
CMMSE	Chinese Mini-Mental State Examination
CT	Computer Tomography
DCC	Day Care Centre
DDCC	Dementia Day Care Centre
FDW	Foreign Domestic Worker
HC	Home Care
HIC	High Income Countries
IADL	Instrumental Activities of Daily Living
LC	Low Income Countries
LMIC	Lower and Middle Income Countries
MCI	Mild Cognitive Impairment
MMSE	Mini-Mental State Examination
MRI	Magnetic Resonance Imaging
PWD	People With Dementia
PWOD	People WithOut Dementia

RCF	Residential Care Facility
RUD	Resource Utilization in Dementia
SE	Standard Error
SG$	Singapore Dollars
UK	United Kingdom
UMIC	Upper Middle Income Countries
USA	United States of America
US$	United States Dollars

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DEFINITIONS OF TERMS

This section will provide the contextual definition of the significant terms that will be used in this thesis.

Alzheimer’s disease: Alzheimer's disease is a type of dementia that causes problems with memory, thinking and behavior. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks (Alzheimer’s Association, USA, 2016).

Barthel Index: The Barthel Index (BI) serves as a measure of daily living activities in relation to personal care and mobility of the patient (Lubke, N., Meinck, M. and von Renteln-Kruse, W.,2004).

Cost of illness: Cost of illness study is an economic study in the medical literature. The aim of a cost of illness study is to identify and measure all the costs of a disease, including the direct and indirect dimensions. The output which is generally expressed in monetary terms, is an estimate of the total burden of a disease to society (Byford, S., Torgerson,D. & Raftery, J., 2000).

Dementia with Lewy bodies: Dementia with Lewy bodies (DLB) is a type of progressive dementia that leads to a decline in thinking, reasoning and independent function because of abnormal microscopic deposits that damage brain cells over time (Alzheimer’s Association, USA, 2016).

EU member countries (G20): Cyprus, Austria, Belgium, Croatia, Czech Republic, Denmark, Finland, Greece, Ireland, Luxembourg, Malta, Netherlands, Portugal, Slovenia, Spain, Sweden, Poland, Romania, Slovak Republic, Bulgaria, Estonia, Hungary, Latvia, Lithuania.

Formal care: Services provided by trained, licensed and qualified professionals and these services are controlled by the state or other types of organization. Caregivers have contracts specifying care responsibilities and are paid and entitled to social rights and working regulations. Caregivers' tasks are specified according to professional qualification and they have a time schedule and go 'off duty' (Viitanen, 2007)**.**

G20 countries: Argentina, Australia, Brazil, Canada, China, France, Germany, India, Indonesia, Italy, Japan, Mexico, Russia, Saudi Arabia, South Africa, South Korea, Turkey, the United Kingdom and the United States. The EU is the 20th 'country' in the G20,

G7 countries: Canada, France, Germany, Great Britain, Italy, Japan, and the United States

Informal care: Care that is mainly provided by family, close relatives, friends or neighbours. These caregivers are non-professionals and not trained to provide care; but in some cases they may benefit from special training. They have no contracts regarding care responsibilities and often are not paid. They perform a wide range of tasks (also performed by formal caregivers) including emotional support and assistance and there are no limits to time spent on care – never/rarely officially 'off duty' (Viitanen, 2007)**.**

Members (18) of the ADI Asia Pacific region: Australia, Bangladesh, China, Chinese Taipei, Hong Kong SAR, India, Indonesia, Japan, Macau SAR, Malaysia, Nepal, New Zealand, Pakistan, Philippines, Singapore, Republic of Korea, Sri Lanka and Thailand.

Resource Ultilisation in Dementia (RUD): The RUD is a questionnaire instrument to estimate the amount of informal care provided by caregivers to dementia patients (Wimo, A., Jonsson, L., & Zbrozek, A.,2010).

Vascular Dementia: Vascular dementia is a decline in thinking skills caused by conditions that block or reduce blood flow to the brain, depriving brain cells of vital oxygen and nutrients (Alzheimer's Association, USA, 2016).

WAR: World Alzheimer's Report

Chapter One

Background and Aims

Introduction

The world population has been ageing at an accelerated rate and most people are expected to live into their 60s and beyond. Between 2015 and 2050, the proportion of the world's population over 60 years will nearly double from 12% to 22% (World Health Organization, 2015). With an increasing life expectancy, globally the number of individuals with dementia is expected to rise to about 131.5 million by 2050 (Alzheimer’s Disease International, 2015). Mehta (2005) posited that the majority of the world’s older people will be living in Asia by the 21st century. This is due to the dual effects of higher life expectancy (combined with high out-migration rates) and low fertility rates (United Nations, 2013).

The increasing prevalence of dementia brings increasing costs, not just in terms of formal costs such as hospitalizations, but also in informal, often more hidden costs, such as the foregone work opportunities of family caregivers. This thesis explores the current state of costs in Singapore, for individuals with and without dementia, and compares the costs of dementia care in Singapore with previous estimates of costs from around the globe. These countries include High Income Countries (HICs) and Lower Middle Income Countries (LMICs).

The global population of older people (aged 60 years or over) is projected to increase by 55.67% over the next 15 years (World Population Ageing, 2015). In absolute numbers, globally the number of older persons (aged 60 years or over) is expected to increase from 0.90 billion in year 2015 to 1.40 billion in year 2030 and close to 2.00 billion in year 2050 (World Population Ageing, 2015; see Figure 1). In

Singapore, the percentage of people who are 65 years and above had been increasing steadily by 7.8 percentage points over the last 44 years (see Figure 2).

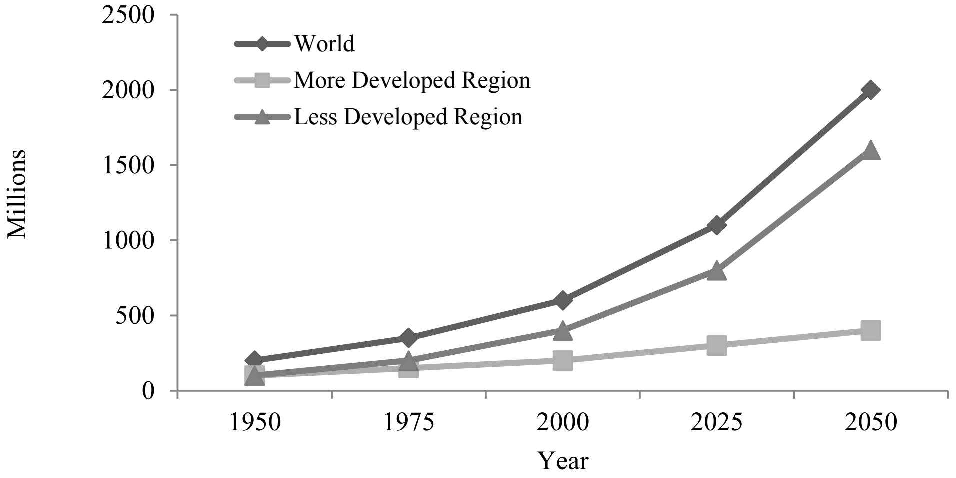

Figure 1. Population aged 60 or over; world and development regions 1950-2050 (World Population Ageing, 2015)

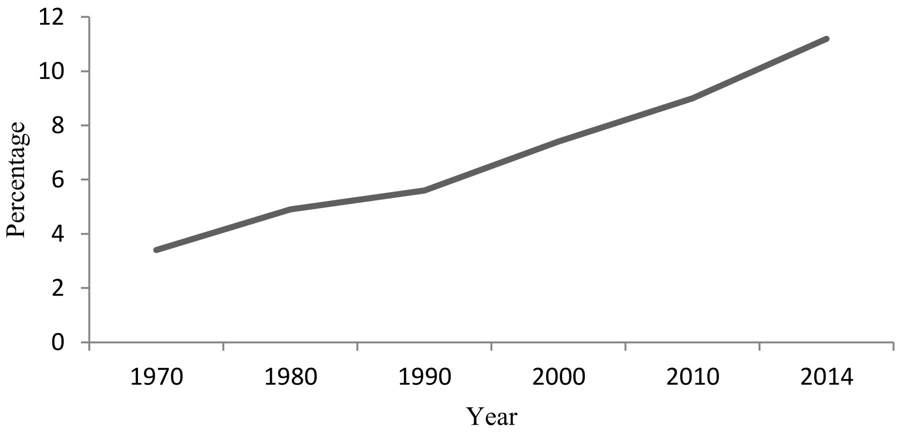

Figure 2. Population of people 65 years and above (% of total) (Singapore Department of Statistics, 2015c)

Cognition and Dementia

The management of dementia has been increasingly studied in many parts of the world, perhaps partly owing to the ageing populations around the world. Research on ageing and disease has brought about knowledge of a more accepting attitude toward the elderly population and the accompanying problems of ageing. Yet to date, no cure has been found and the prevalence continues to increase. Therefore, the World Health Organization has classified dementia as a public health priority and worldwide health challenge (World Health Organization, 2012).

The main risk factor for cognitive impairment is ageing. Other risk factors include diabetes, high blood pressure, high cholesterol, tobacco use, alcohol use, depression, and diet and exercise (U.S. Preventive Task Force, 2014).

The relationship between increasing age and cognitive impairment is well known and has been explored (Fratiglioni et al., 2000; Prince et al., 2013). Cognitive impairment is also associated with higher usage of health and social services (Ganguli et al., 1993).

Mild cognitive impairment (MCI) involves memory problems that are greater than normal but that these problems do not interfere with a person’s ability to carry out activities of daily living (ADL; U.S. Preventive Task Force, 2014). Symptoms of mild cognitive impairment are difficult to detect because they do not interfere with daily life activities.

Dementia is a much more serious problem compared to mild cognitive impairment. It is the loss of thinking, remembering and reasoning skills to the point where it becomes difficult for a person to carry out life tasks and activities such as bathing or dressing oneself. People with dementia may also have behavioral and psychological problems (U.S. Preventive Task Force, 2014). People with dementia

(PWD) tend to have more needs than people without dementia (PWOD; Philp et al., 1995).

Due to the global ageing population, the absolute number of people with dementia has increased from 46.8 million in 2015, and is projected to increase further to 74.7 million in 2030 and 131.5 million in 2050 (Alzheimer's Disease International, 2015; see Figure 3).

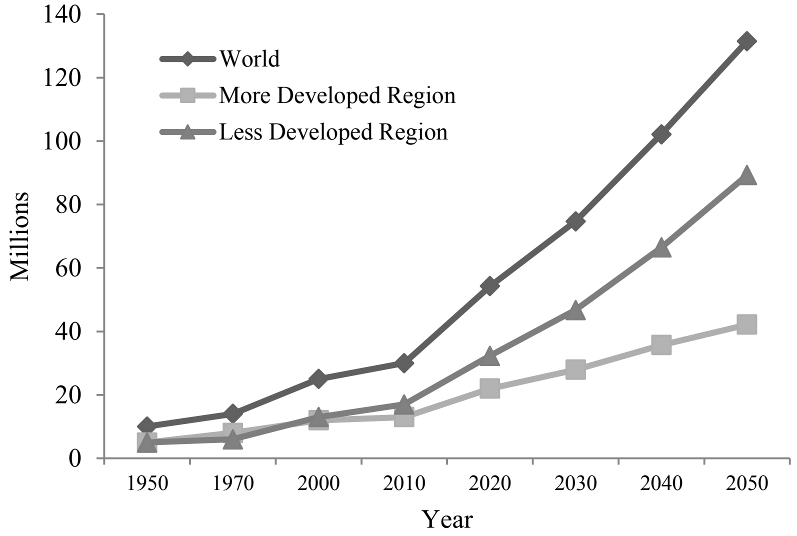

Figure 3. Dementia occurrence (millions) and forecast of dementia occurrence worldwide in less developed and more developed regions from 1950 to 2050 (Alzheimer's Disease International, 2015)

Dementia is a term describing a group of disorders that includes Alzheimer's disease and other subtypes. It is not a disease. The patient who has dementia experiences a gradual decline in memory and other cognitive functions. These may include impairment in language or memory function severe enough to reduce a person's ability to perform everyday activities (Alzheimer's Association, USA, 2016). These problems will decrease the well-being of the patients and their caregivers, and ultimately put strain on family relationships, friendships as well as cause high healthcare costs (World Health Organization, 2015).

Causes & Types of Dementia

The World Health Organization (2015) indicates that dementia is not caused by a single factor. It can be caused by multiple diseases, often showing slightly different symptoms. These symptoms may sometimes overlap, so it is difficult to detect that the problem is dementia. Dementia is caused by damage to brain cells (Alzheimer’s Association, USA, 2016). This damage interferes with the ability of brain cells to communicate with each other. When brain cells cannot communicate normally, thinking, behavior and feelings can be affected.

Different types of dementia are associated with particular types of brain cell damage in particular regions of the brain (Alzheimer’s Association, USA, 2016). In Alzheimer's disease, high levels of certain proteins inside and outside brain cells make it hard for brain cells to stay healthy and to communicate with each other. The brain region called the hippocampus is the center of learning and memory in the brain. The brain cells in this region are often the first to be damaged, which explains that memory loss is often one of the earliest symptoms of Alzheimer's (Alzheimer’s Association, USA, 2016).

The Alzheimer’s Association, USA (2016) noted that while most changes in the brain that caused dementia are permanent and worsen over time, thinking and memory problems caused by the following conditions may improve when the condition is treated or addressed. These include depression, medication side effects, excessive use of alcohol, thyroid problems and vitamin deficiencies.

The most common type of dementia is Alzheimer’s disease, which makes up 60% to 80% of cases globally (World Health Organization, 2015). Alzheimer’s disease is characterized by changes in the brain due to a build-up of abnormal plaques and tangles. Alzheimer’s disease can be either *sporadic* or *familial* (Alzheimer’s Australia, 2012). *Sporadic* Alzheimer’s disease can affect adults at any age, but usually occurs after age 65 and is the most common form of Alzheimer’s disease (Alzheimer’s Australia, 2012).

Vascular dementia. This is the second most common cause of dementia which accounts for 20% to 30% of cases. It is caused by decreased blood flow to the brain which deprives brain cells of essential nutrients and oxygen (Draper, 2011; Seeher, Withall, & Brodaty, 2011). People with vascular dementia usually experience a decline in their cognitive functions more rapidly than people with Alzheimer’s disease. Often they die from a heart attack or major stroke (Alzheimer’s Australia, 2012).

Frontotemporal dementia. This accounts for 5% to 10% of dementia cases. No single pathology has been identified with the disease caused by the degeneration of cells in the brain’s frontal or temporal lobes (Draper, 2011; Seeher, Withall, & Brodaty, 2011). Although frontotemporal dementia can affect people at any age, it usually begins between 40 and 65 years of age, and is a significant cause of dementia in younger people (Alzheimer’s Australia, 2012). Pick’s disease is a type of frontotemporal dementia named after the German neurologist who first described it in 1892 (Alzheimer’s Australia, 2012).

Dementia with Lewy bodies. This accounts for less than 5% of dementia cases (Draper, 2011; Seeher, Withall, & Brodaty, 2011). Lewy body disease is caused by the degeneration and death of nerve cells in the brain. The name comes from the presence of abnormal spherical structures called Lewy bodies which develop inside nerve cells. It is thought that these may contribute to the death of the brain cells (Alzheimer's Australia, 2012). Lewy body disease differs from Alzheimer's disease in that the progression of the disease is usually more rapid. However, like Alzheimer's disease, it is a degenerative condition eventually leading to complete dependence (Alzheimer's Australia, 2012).

Younger onset dementia. This is also referred to as early onset dementia, and is the term used to describe any form of dementia diagnosed in people under the age of 65. Few studies into the prevalence of younger onset dementia have been conducted globally, often because epidemiological studies of dementia frequently exclude people under the ages of 65 or 60 (Alzheimer's Australia, 2014).

Elderly care in Singapore

The government plays an important role in the provision of affordable healthcare services to the elderly population in Singapore. There are public clinics (polyclinics) in every town which cater to the community in the estate. Healthcare services for the elderly can be broadly classified as either residential or community healthcare services in Singapore. These services are provided by both voluntary welfare organizations (VWO) and private sector operators (Ministry of Health, 2007).

Residential healthcare services for the elderly are for the elderly who become frail, sick and bedridden and who may need residential healthcare facilities when they are unable to care for themselves or be cared for within their own homes. These facilities include community hospitals, chronic sick hospitals, nursing homes, inpatient hospice care and respite care.

Community healthcare services for the elderly mainly cater for those who prefer to live in a familiar environment with their family members and friends. However, if the elderly or the family is unable to provide care to the elderly, community healthcare services may be required to help the elderly remain at home (Ministry of Health, 2007).

These community healthcare services may be provided at home or at a centre. **Home-based** healthcare services are provided within the homes of the older persons. They include medical, nursing and palliative care services, such as Home Medical, Home Nursing and Home Hospice Care Services. **Centre-based** healthcare services are provided within a centre. The elderly attend these centres during the day, usually on a regular basis, but go back to their own homes for the night. These centres include Day Rehabilitation Centres, Dementia Day Care Centres (DDCCs), and Psychiatric Day Care Centres and Rehabilitation Homes.

Dementia in Singapore

In Singapore, the prevalence rate of people with dementia aged 65 years and above is about 6.2% (Alzheimer's Disease Association, Singapore, 2016). There are currently 40,000 PWD in Singapore. This figure is expected to more than double to 92,000 in 2030 and 187,000 in 2050 (Alzheimer's Disease Association, Singapore, 2016; see Figure 4). Little is known about the burden of dementia care in Singapore. The Alzheimer's Association monitors prevalence of dementia. The only published study of the burden of care for dementia specifically in Singapore (Chong et al, 2013) provided information on some aspects of financial burden. However more data on costs is needed and the current research program aims to address that gap.

Many of these PWDs prefer to be cared for by their family members at home rather than be admitted to a nursing home (Tew Tan, Luo, Ng, & Yap, 2010). Hence, the cost of informal care for these PWDs is of high importance in Singapore as it is largely borne by individual families of PWD. This is, in many ways, a hidden cost of the illness. However, currently there is no voluntary or mandatory screening program for the elderly population above 65 years of old for dementia in Singapore. To date, there is no study conducted here on the roles of FDWs in the cost savings of caring for the patients with severe dementia in Singapore.

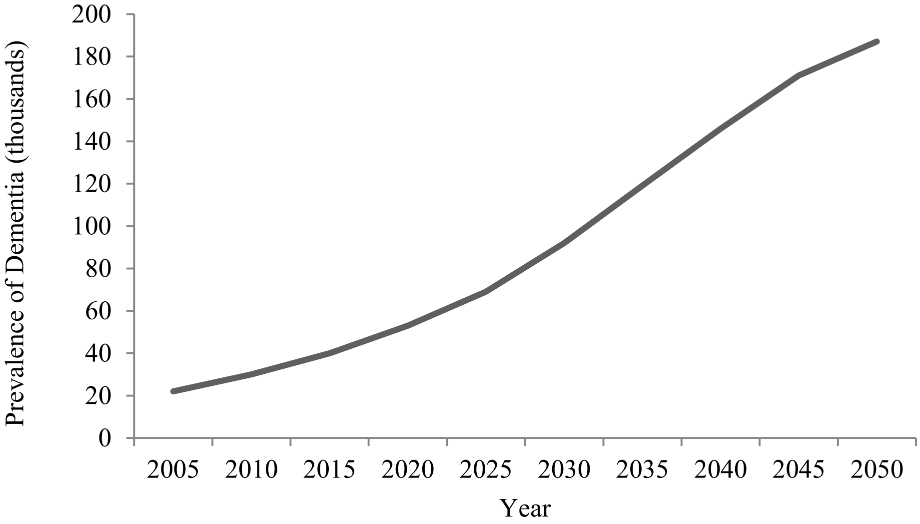

Figure 4. Prevalence of Dementia in Singapore (Alzheimer’s Disease Association, Singapore, 2016)

Informal costs of care

Family or informal caregivers are usually involved in the care of the elderly. As a result, informal caregivers of people with dementia have increasingly assumed the responsibility of care at home and provision of financial and social support (Vaingankar et al., 2013).

Informal caregivers face numerous challenges and considerable stress, including financial burden, increased vulnerability to emotional and physical burnout, and disruption in household and work routines as a result of the demands of caregiving (Brodaty & Donkin, 2009; Chan, 2010; Ornstein & Gaugler, 2012; Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013). Several studies have highlighted the plight of informal caregivers; some have reported a range of caregiver burden (Kurasawa et al., 2012; Mehta, 2005), while others have presented them in the context of deinstitutionalization of care (Bakker et al., 2012; Tew, et al., 2010).

Informal care cost is an important component of the total care cost for PWDs. However, it is not easy to quantify this component due to different methods of valuations and estimations. Informal care time generally includes the amount of time spent with the patient by the primary informal caregiver. However, the provision of this informal care has gradually shifted to more than one caregiver (Prince et al., 2013). This process has complicated the valuation for the caregiver's time.

Research Aims

General Aims

This thesis has two general aims:

1. To quantify and explore the informal and formal cost of care for people with mild, moderate to severe dementia in Singapore.
2. To quantify and explore the informal cost of care for people without dementia (PWODs) in Singapore, and further, to compare these costs to those PWD.

Specific Aims

The specific aims of this thesis can be summarized below:

1. To quantify the total cost of care of PWDs in DCCs or DDCCs with and without FDWs in Singapore
2. To quantify the total cost of care of PWDs without DCCs or DDCCs with and without FDWs in Singapore
3. To analyse the cost of residential care facilities (RCFs) for PWDs in relation to their cognitive and functional capabilities.
4. To detect and describe if there are any differences in the cognitive and functional capabilities of PWDs in the above three settings.
5. To compare the cost of informal care of PWDs and PWODs in Singapore.
6. To decide if cost is a barrier to screening for dementia.

Background & Rationale

The percentage of elderly residents in Singapore who are aged 65 years and above stood at 7.4% of the resident population in 2000 (Singapore Department of Statistics, 2015). This figure has increased to 11.2% in 2014. The ageing population is expected to increase further and the prevalence of dementia is also expected to increase with this ageing population. The number of PWDs in Singapore is expected to balloon more than double to 92,000 by 2050 from 2015. This will pose a heavy burden on national healthcare, social services and the economy.

A survey conducted by the National Health Group in 2010 indicated that about 20% of caregivers spend more than 12 hours daily attending to persons with chronic medical conditions such as dementia (The Straits Times, Sep 2012). This figure is slightly higher than the average global figure of about 10 hours per day.

With this expected increasing trend of more PWD in Singapore, there is also a need to examine the total costs of care incurred by these PWDs, caregivers and society.

Currently there is limited understanding of and research on informal cost of care by PWDs and PWODs in Singapore.

Scope of Thesis

This thesis seeks to quantify and explore the informal and formal cost of care for people with mild, moderate to severe dementia in Singapore and also for PWOD. A comparison on the informal cost of care between these two groups will be conducted. Factors affecting the cost of care for these PWDs and PWODs will be explored and analyzed in the chapters. With a view to studying the nature and comparing the cost of care for elderly people in Singapore, a literature review on the cost of care in low and middle income countries (LMIC) and high income countries (HIC) will be included. In order to find out if screening is a cost barrier in detecting dementia for the elderly, a separate chapter will be covered on early screening for elderly.

Summary

Chapter One will introduce the basic concepts and definitions and causes of dementia. A comparison of two scenarios will be presented, comparing the world ageing population and global prevalence of dementia with those in Singapore. Thereafter, different types of healthcare services and informal care for elderly people will be explored.

Chapter Two will cover a literature review on the global and Asia Pacific region prevalence and incidence of dementia and existing global studies of costs of care. A study on costs of care will be compared between low and middle income countries (LMIC) and high income countries (HIC), with three countries selected for cost comparison. The costs associated with caring for PWDs are different between countries and dependent upon factors like urbanization, cultural and family structures, public health infrastructure, care services, gross domestic product, and government systems (Alzheimer's Disease International, 2014). However, this chapter will focus on two of these factors: cultural structure and care services for PWDs and PWODs.

Cultural structures between countries in ways of caring for elderly with dementia also play a contributing role and hence affect the costs of informal care for them. In this chapter, highlights on some cultural structures and differences in four countries will be covered: Japan, Turkey, the United States of America (USA) and Singapore. Singapore is of particular interest as it is a developed and heterogeneous country where little is known to date about the costs of dementia care (which will be covered in details in the next Chapter Three). Japan is selected for comparison as a developed but culturally homogenous and economically closed country, while Turkey is selected as a developing country for comparison between developed and developing countries. The USA is selected for comparison as a developed and heterogeneous country and economically open country. To explore these cultural structures and differences, a literature review details the traditions of care in Japan Turkey, and USA followed by an analysis of data collected in Singapore to establish the informal and formal care costs of dementia elderly.

Chapter Three will report a specific study on the total costs of care for 51 PWD with mild, moderate and severe dementia in Singapore. This is an analysis of 346 consecutive eligible existing mental patients attending a follow up consultation with a psycho-geriatrician in a government funded public mental health institution (the Institute of Mental Health, Singapore) during a four-month period from August to November 2015. Valuations and measurements of total informal and formal costs of care for PWD by severity will be reported. Caregivers' and PWD characteristics, time spent by caregivers on Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), and supervision, healthcare utilisation, use of DCCs or DDCCs, full time residential care facilities (RCF) and FDWs in caring to these PWDs are conducted. Factors affecting costs of informal care like use of DCCs, DDCCs, RCF and FDWs are analysed. Four scenarios are simulated on the breakdown of patient's severity of dementia by type of care and costs with the objective to discovering the difference in costs of care for PWD based on care type and severity of dementia. A correlation of costs of care with Barthel Index and Chinese Mini Mental State Examination (CMMSE) will be reported evaluating the association of functional and cognitive impairment with informal costs of care in Singapore. A logarithm transformation cost function is conducted with CMMSE and Barthel Index. A comparison of the informal cost of care in Singapore is conducted vis-à-vis USA, the United Kingdom (UK), Japan and Turkey.

Chapter Four will report on a second specific study of the informal cost of care of PWOD in Singapore. The purpose of this chapter is, firstly in Study 1, to evaluate the costs of care of PWOD, and secondly in Study 2, to compare these costs with PWD in Singapore reported in Chapter Three. The aim is to increase the utility of the data from Chapter Three by providing a comparison of data on costs of care of PWD and PWOD in Singapore. This chapter starts with a literature review on factors affecting the cost of care for PWOD in developed countries including USA, UK and Canada, with the objective of comparing these factors with those PWOD in Singapore. Using a sample size of 137 PWOD from a public hospital in a community dwelling setting, the informal cost of care is valued and measured and compared with those PWD in Chapter Three. Caregivers' characteristics, healthcare utilization, ADL, IADL and supervision time spent by, use of FDWs and total cost of care are analysed and compared with those PWD as completed in Chapter Three. A multiple regression is conducted to analyse the factors affecting the total informal cost of care for PWOD in Singapore.

Chapter Five will conduct a literature review on screening with the objective to find if cost is a barrier to screening in Singapore. This chapter will introduce the basic concepts on diagnosis of screening, types of screening done globally and in Singapore, instruments, limitations, harms and benefits of screening. Thereafter, this chapter will conclude with a study on the cost of screening on PWD and results will be analysed and reported vis-à-vis Singapore.

Chapter Six will conclude and summarise the discussions and findings from each earlier chapter and conclude with the implications on each finding and areas for further research. The summary and implication of each finding will include: 1) a comparison on informal cost and formal cost of care for PWD; 2) an examination of the components of formal cost of care; 3) an examination of healthcare utilisation and other chronic health conditions and formal cost of care of PWD; 4) estimates valuing formal care and measuring medication cost; 5) an examination of the relationship between informal costs and disease severity of PWD; 6) an examination of the association of informal costs with cognitive and functional capabilities of PWD; 7) an analysis of impact of RCFs and FDWs on informal cost of care for PWD and PWOD; 8) an analysis of FDWs on informal cost of care for PWD and PWOD; 9) an analysis of the importance of support by family caregivers for PWD and PWOD; 10) an analysis of impact of DCCs or DDCCs on informal cost of care for PWD; 11) a comparison on the differential costs of care (by disease severity) for PWD using DCCs, DDCCs, FDWs; 12) a comparison of informal cost of care in Singapore vis-à-vis the HICs and LMICs; 13) an analysis of risk factors related to informal cost of care; 14) an examination of informal cost and the cost of screening; 15) an estimation of the informal cost of PWDs in a private community-setting versus PWODs in a public community dwelling; 16) estimates of total cost of care of dementia in Singapore; 17) an examination of the informal costs, in terms of caregiver time, of caring for community-dwelling PWODs and 18) a comparison of the impact of having FDWs on informal cost of care for PWOD compared to PWD. To the best of my knowledge, this will be the first study that has conducted such a detailed analysis in Singapore, covering all the above findings, including some salient findings such as the impact of the different settings of RCFs, DCCs, DDCCs and FDWs on the cost of informal care for PWD; estimates on the informal cost of PWD based on disease severity (none, mild, moderate and sever), comparison of informal cost of PWD and PWOD and an examination on healthcare utilisation and other chronic health conditions and formal cost of care of PWD here.

Chapter Two

Literature review: Global Costs of care for Dementia

Introduction

Demographic ageing is a global process due mainly to increasing life expectancy and improved health care services (Alzheimer's Disease International, 2015). Many people are now living longer and healthier lives. Hence the global population has more elderly people. Dementia mainly affects elderly people after the age of 65 or later-onset dementia, although there is a growing awareness of cases of dementia in people before the age of 65 or young-onset dementia (up to 59 years of age).

With more elderly people living longer globally, McDaid (2009) noted that it is important to recognize that there are both rewards and difficulties associated with caregiving for these elderly people. This desire and willingness of family members to provide care can mean that policy makers and other stakeholders are tempted to treat informal care as a resource that is easily available (McDaid, 2009). However, it can entail significant economic costs for individuals and society. Economic analysis is primarily concerned with the opportunity costs of caring; i.e., what would caregivers be doing with their time if they were not caring for the PWD. For the caregivers, this is a cost of informal care.

Caregiving in Dementia

Coen, O'Boyle, Coakley and Lawlor (2002) posited that caring for someone with dementia can sometimes be a 24-hour-a-day activity. While the availability of family caregivers may reduce the need for professional support, caregivers will incur a loss of time (and hence a cost) which they could have used for work, or to pursue leisure activities.

Individuals may become isolated from their social network of family and friends as the disease progresses, and caregiving becomes a full-time occupation (Leinonen, Korpisammal, Pulkkinen, & Pukuri, 2001). Evidence of high levels of distress and depression among caregivers of people with dementia can be seen in many studies of service users and in community surveys (Coen, O'Boyle, Coakley, & Lawlor, 2002; Livingston, Manela, & Katona, 1996; Murray, Schneider, Banerjee, & Mann, 1999). They may also incur additional out-of-pocket expenses to support a relative financially. In addition, there can also be adverse impacts on their physical health, for example, as a result of the strains of helping an individual cope with essential activities of daily living.

PWDs are often cared for by their family members at home. These caregivers (mainly the spouse, sibling or children) often describe the caregiving experience as enduring stress and frustration (Butcher, Holkup, & Buckwalter, 2001). There are many definitions of caregivers' burden (CB; Stucki & Mulvey, 2000; Zarit, Reever, & Bach-Peterson, 1980).

Zarit, Reever, and Bach-Peterson (1980) defined CB as a state of mind where the caregiver had to necessary caring tasks or restrictions that cause discomfort for themselves in their caregiving roles, while Stucki and Mulvey (2000) referred to CB as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member. Buhse (2008) defined CB as a multidimensional response, naming aspects of physical, psychological, emotional, social, and financial stress associated with the caregiving experience. All these definitions of CB had one term in common - all are linked to the mental distress or psychological stress resulting from caring for their loved ones. CB is different from caregiving. The former is usually a term used to describe a mind phenomenon (Buhse, 2008), while the latter refers to the activities and experiences involved in providing help and assistance to family members who are unable to provide for themselves (Pearlin, Mullan, Semple, & Skaff, 1990) but excludes the psychological distress that may come from it. CB is often associated with the caregiver's perception of activities and resultant stress. Thus, CB is influenced by many psychosocial factors such as relationship with the loved ones, social environment, and culture. Due to the psychological stress and physical exhaustion of taking care of their loved ones with dementia, caregivers also need mental support for themselves. These caregivers often feel overwhelmed, ignored, and neglected in their roles of caregiving for their loved ones, and these feelings become an additional burden for them (Courts, Newton, & McNeal, 2005).

Caregivers experienced high rates of depression, anxiety and psychiatric morbidity (Brodaty & Donkin, 2009). In developed countries, rates of depression vary between 23% and 85% with rates of anxiety between 16% and 45% (Clare, Wilson, & Carter, 2002). In developing countries, the range is closer and higher with psychiatric morbidity ranging from 40% to 75% (The 10/66 Dementia Research Group, 2004). Caregivers are often associated with poor outcome of CB such as psychological sickness like depression, distress and lower quality of life (Schulz, Boerner, Shear, Zhang, & Gitlin, 2006; Gitlin, Hauck, Winter, Dennis, & Schulz, 2006). PWD are associated with poor outcome of CB such as poor quality of life and early placement into full time RCFs (Gaugler, Kane, Kane, & Newcomer, 2005; Yaffe et al., 2002).

According to Murray, Schneider, Banerjee and Mann (1999), it is thus important to include the full costs of caring when decision makers have to determine the cost-effectiveness of introducing specific services or programmes to support family caregivers, or providing other interventions. It also provides an indication of the costs that may fall on statutory services in future, if there is a shortage of such caregivers due to the ageing population in most European countries (Murray, Schneider, Banerjee, & Mann, 1999).

However, McDaid (2001) noted that because of methodological difficulties in estimating informal care costs, and also a narrow focus solely on the health care system alone, the cost to family caregivers has often been ignored within economic analyses. In particular, identifying the best alternative use of time is not always easy, especially if a family caregiver already has been responsible for an individual, for example, a spousal caregiver already undertaking a range of activities that benefit the whole household. This has led to a variation in estimates of the cost of caring for Alzheimer's Disease and other dementias ranging from 36% to 85% t of total costs in one review (McDaid, 2001).

Global Prevalence of Dementia

An estimated 46.8 million people globally were living with dementia in 2015. This number is predicted to almost double every 20 years, reaching 74.5 million in 2030 and 131.5 million in 2050 (Alzheimer's Disease International, 2015; see Table 1).

Alzheimer's Disease International (2015) has estimated that most of the increases were in LMIC and will continue to be so. As of now, there are already 58% of people with dementia living in LMIC. By 2030 and 2050, this figure will rise to 63% and 68% respectively.

Table 1

Number of people with dementia (millions)

World Bank Income Group	Number of People with Dementia (millions)							
	2015	2020	2025	2030	2035	2040	2045	2050
Low Income	1.19	1.42	1.68	2.00	2.41	2.90	3.55	4.35
Low Middle Income	9.77	11.52	13.72	16.35	19.48	23.12	27.18	31.54
Upper Middle Income	16.32	19.36	23.33	28.39	34.28	40.43	46.90	53.39
High Income	19.50	21.97	24.73	27.95	31.72	35.71	39.14	42.18
World	46.78	54.27	63.45	74.69	87.88	102.15	116.78	131.45

Note: From the 2015 World Bank income classification (Alzheimer's Disease International, 2015).

In 2015, on a global basis, the estimated number of PWD is highest in Asia (23.3 million), Europe (10.5 million), North & Latin America (9.4 million) and Africa (4.0 million; Alzheimer's Disease International, 2015).

Table 2

Estimated number of people with dementia (2015, 2030 and 2050) and proportionate increases (2015-2030 and 2015-2050) according to wealth (GNP)

	People with dementia (millions) (% of world total)			Proportionate increase (%)	
Region	2015	2030	2050	2015-2030	2015-2050
G7	12.88 (28)	18.43 (25)	26.28 (20)	43	104
G20	37.47 (80)	58.99 (79)	99.14 (75)	57	165
G20 excluding G7	24.59 (53)	49.56 (54)	72.86 (55)	65	196
Rest of the world (excluding G20)	9.31 (20)	15.70 (21)	32.31 (25)	69	247
World	46.78 (100)	74.69 (100)	131.45 (100)	60	181

Note: From Alzheimer's Disease International, 2015

From diagnostic evidence, Alzheimer's Disease is skewed towards becoming a "Middle Income" country problem, based on the estimated number of PWD from

2015 -2030 and 2015-2050 and proportionate increases according to wealth (GNP) during the same periods (Citation). The largest increases in dementia prevalence over the next 15 years are in the G20 countries which are typically the HMIC (High Middle Income Countries) and LMIC (Lower Middle Income Countries; see Table 2).

Global Incidence of Dementia

On an annual basis, there were more than 9.9 million new cases of dementia globally been reported, with one new case every 3.2 seconds recorded in 2015 (Alzheimer's Disease International, 2015). These new cases were 30% higher than those estimates obtained five years ago in 2010. Alzheimer's Disease International (2015) noted Asia had the highest increase (4.9 million or 49% of the total) in new cases, with Europe having 2.5 million (25%), the Americas having 1.7 million (18%), and Africa having 0.8 million (8%). All regions (including Asia, Africa, Americas) showed increases in new cases of dementia except Europe, which had a decrease.

Global Economic Impact of Dementia

The personal, social and economic consequences of dementia are enormous. Dementia leads to increased long-term care costs for governments, communities, families and individuals, and to losses in productivity for economies (Alzheimer's Disease International, 2015). The global costs of dementia had increased 35.4% from US$604 billion in 2010 to US$818 billion in 2015, which was 1.0% of global gross domestic product (Alzheimer's Disease International, 2015). This figure included costs attributed to informal care (unpaid care provided by family and others), direct costs of social care (provided by community care professionals, and in residential home settings) and the direct costs of medical care (the costs of treating dementia and other conditions in primary and secondary care).

Global Cost of Dementia

By 2030, the cost of caring for PWD globally could reach more than US$1.2 trillion, which could undermine social and economic development throughout the world (World Health Organization, 2015). Although most people with dementia live in LMIC, about 90% of these costs were in HIC (Alzheimer's Disease International, 2015). LMIC have larger costs associated with informal care for PWD whilst care costs in HIC are relatively evenly distributed across informal and social care (World Health Organization, 2012). Also, the costs associated with caring for PWD are different between countries and dependent upon factors like urbanization, cultural and family structures, public health infrastructure, care services, gross domestic product, and government (Alzheimer's Disease International, 2014).

The World Bank (2015) revises analytical classification of the world's economies annually based on estimates of gross national income (GNI) per capita for the previous year. The updated GNI per capita estimates are also used as input for the World Bank's operational classification of economies that determines lending eligibility. As of 1 July 2015, low-income countries or LIC are defined as those with a GNI per capita, calculated using the *World Bank Atlas* method of $1,045 or less in 2014; middle-income countries (MIC) are those with a GNI per capita of more than $1,045 but less than $12,746; high-income countries (HIC) are those with a GNI per capita of $12,746 or more. Lower-middle-income and upper-middle-income countries (LMIC) are separated at a GNI per capita of $4,125 (World Bank, 2015).

Table 3

Worldwide costs of dementia in 2010 and 2015 (billion US$)

Year for cost estimates (basis for prevalence estimates)	**2010 (WAR 2009)**		**2015 (WAR 2015)**	
World Bank Country Classification Year	2010		2010	
	US$ (billions)	Per cent	US$ (billions)	Per cent
Low Income	5.2	0.9	6.6	0.8
Lower Middle Income	41.2	6.8	57.1	7.0
Upper Middle Income	49.4	8.1	84.5	10.3
High Income	510.9	84.2	669.6	81.9
Total	606.7	100.0	817.9	100.0

Note: From World Bank country classification 2010 and adjusted prevalence figures for 2010. (Alzheimer's Disease International, 2015)

According to the World Alzheimer Report, 2015, the annual cost a PWD increased steeply with the country income status from 2010 to 2015 (see Table 3). In 2015, the mean cost for a PWD was US$43,680 in G7 countries (see Definition of Terms, p. xxiv), US$20,187 in G20 countries (see Definition of Terms, p. xxiv) and US$ 6,757 in countries excluding G7 and G20.

Prevalence of Dementia in Asia Pacific Region

Based on Alzheimer's Disease International (ADI)'s categorization of regions, the population of the Asia Pacific region in 2015 was estimated at 4 billion. Estimates showed that more than 11% of the population in the region was over 60 years of age (United Nations, 2013; World Health Organization, 2014). ADI expected that by 2050 a quarter of the total population in the Asia Pacific region will be aged 60 years or older.

The number of PWD in the Asia Pacific region is expected to increase from about 23 million in 2015 to almost 71 million by 2050. By 2050, this region would have more than half of PWD globally (135 million; Alzheimer's Disease International, 2015; see Table 4).

Cost of Dementia in Asia Pacific region

Alzheimer's Disease International (2014) has estimated the total cost for dementia in the Asia Pacific region in 2015 at US$185 billion. These figures are likely to increase as the numbers of PWD increase over the years in emerging countries with large populations like India, China and Indonesia (see Tables 4 and 5).

Table 4

Estimated costs and number of people with dementia in the Asia Pacific region

	Projected Population (‘000)	Estimated Number of people with Dementia (‘000)			Estimated Costs (US$ millions)
	Y2015	Y2015	Y2030	Y2050	
ADI Members					
Australia	23,923	328	520	864	12,892
Bangladesh	160,411	460	834	2,193	321
China, P.R.	1,401,587	10,590	18,116	32,184	44,619
China, Hong Kong SAR	7,314	115	212	436	3,227
China, Macau SAR	584	4	11	26	158
Chinese Taipei	23,380	260	461	840	6,990
India	1,282,390	4,031	6,743	12,542	4,620
Indonesia	255,709	1,033	1,894	3,979	1,777
Japan	126,818	3,014	4,421	5,214	93,240
Malaysia	30,651	123	261	590	705
Nepal	28,441	78	134	285	52
New Zealand	4,596	60	96	154	1,199
Pakistan	188,144	450	712	1,422	642
Philippines	101,803	301	568	1,149	599
Singapore	5,619	45	103	241	1,664
Republic of Korea	49,750	462	974	2,113	8,676
Sri Lanka	21,612	147	262	463	230
Thailand	67,401	600	1,117	2,077	1,810
ADI members total	3,780,133	22,100	37,438	66,772	183,422
Non ADI members	211,660	1,179	1,970	4,209	1,446
Total Asia Pacific	3,991,793	23,279	39,409	70,981	184,868

Note: From Alzheimer’s Disease international, 2015

Table 5

Prevalence and estimated number of people with dementia in Asia Pacific region

	Projected Population (‘000)	**Estimated Number of people with Dementia (‘000)**			**Estimated aggregated cost of Dementia (US$ millions)**
	2015	2015	2030	2050	2015
ADI members	3,780,133	22,100	37,438	66,772	$183,422
Non ADI members	211,660	1,179	1,970	4,209	$ 1,446
Total Asia Pacific	3,991,793	23,279	39,409	70,981	$ 184,868

Note: From Alzheimer’s Disease International, 2014

Amongst the Asia Pacific region in 2015, Japan is estimated to have the highest costs of dementia of US$93.24 billion, followed by China at US$44.62 billion and Australia of US$12.89 billion (see Table 3). About 70% of the total cost of dementia was from advanced economies in 2015 from the Asia Pacific region. These advanced countries also had 18% of the prevalence of dementia (Alzheimer’s Disease International, 2014)

The costs associated with caring for PWD are different between countries and are dependent upon factors like urbanization, cultural and family structures, public health infrastructure, care services, gross domestic product, and government systems (Alzheimer’s Disease International, 2014). Usually LMIC have larger informal costs of care while HIC costs are evenly distributed between informal and societal costs (World Health Organization, 2012). The next section will focus on two of these factors: cultural structure and care services for PWD and PWOD.

Cultural Structures

Cultural structures between countries in ways of caring for elderly with dementia also play a contributing role, and hence affect the costs of informal care for them. In this chapter, highlights on some cultural structures and differences in four countries will be covered: Japan, Turkey, the United States of America (USA) and Singapore. Singapore is of particular interest it is a developed and heterogeneous country, where little is known to date about the costs of dementia care. This thesis will consider the cultural structures related to dementia care in Singapore in Chapter Three in relation to three other countries' cultural structures which are presented here. Japan is selected for comparison as a developed but culturally homogenous and economically closed country, while Turkey is selected as a developing country for comparison between developed and developing countries. The USA is selected for comparison as a developed and heterogeneous country and economically open country. The literature review explores these cultural structures and differences, and details the traditions of care in Japan Turkey, and USA followed by an analysis of data collected in Singapore to establish the informal and formal care costs of dementia elderly.

The case of Japan

There were 5.2 million Japanese over 65 with dementia in 2015 and this figure will increase to 7.3 million in 2025 (The Japan Times, May 2015). This would translate into one in five of Japan's elderly people, and one in 17 of its total population (Population Pyramid, 2016). Based on a population of 126.57 million people (Population Pyramid, 2016) in 2015, this is estimated at 4.11% of the total population of Japan in 2015.

Japan’s health ministry estimated that the cost of providing health and social care for the nation’s millions of dementia was ¥14.5 trillion in 2014 (US$118 billion) (The Japan Times, May 2015). Nearly half the cost was borne by families. Meanwhile about 440,000 people in Japan left their jobs between 2007 and 2012 to care for their ill or incapacitated parents and other relatives (The Japan Times, Oct 2015). The Ministry is concerned about worker shortages in the future if this trend continues and also highlighted the need for more to be done to care for these PWD.

During the past twenty years in Japan, most people with dementia (75%) are cared for by family members, while the remainder are in residential care facilities (MHW, 1995). Informal care in Japan is unique in the sense that most Japanese households practice Confucianism, which stresses the virtue of filial piety. The eldest son will traditionally inherit the assets of the family from the father; hence, there is tremendous social pressure on the wife of the eldest son (i.e. the daughter in-law), to provide care for the family. This includes taking care of the elderly with dementia at home. Under these circumstances, the Japanese government has not found it a necessity to provide extensive residential care services for the elderly (Arai, 1996).

The concept of Confucianism practice in taking care of the elderly by the eldest sons or daughters-in-law is gradually changing in Japan as the elderly are living longer in Japan. The familial support ratio (that is, the ratio of the number of women aged 40-59 to the total population aged 65-84) is expected to decline substantially between 2005 and 2025. This value, which was 1.30 women per elderly person in 1990, decreased to 0.65 in 2010, a decline of 50% and is projected to decline further by 2025. That is, the potential support that adult daughters (or daughters in-law) might give to elderly parents drops rapidly, especially after 2009 when the large cohort of baby boomers born during 1947-1949 passes out of the 40-59 age group. It is therefore likely that the traditional extended family system that has traditionally provided support to elderly persons may weaken over time (Ogawa & Matsukura, 2005). Although the Government of Japan established in 2000 a Long-term Care Insurance Scheme (LCIS) to alleviate the burden on families taking care of elderly parents at home, the number of households without caregivers younger than 60 is expected to rise, implying that the effectiveness of the LCIS may decline over time (United Nations, 2005).

It is worth noting that according to the United Nations population projections (United Nations, 2005), Japan’s familial support ratio (0.79) was in 2004 the lowest in the entire world, followed by those of Italy (0.80) and Greece (0.81). Projections of these ratios over the next 30 years are highly reliable because the persons involved are already born.

Multi-generational households are still fairly common in Japan (Ogawa, & Matsukura, 2005). According to the 2001 round of the International Survey of Lifestyles and Attitudes of the Elderly, 22% of persons aged 60 or over were living in three-generation households in Japan. By contrast, only 2% of the elderly population in the United States did so, 1% in Germany, and less than 0.5% in Sweden. However, given the rapid demographic shifts that have already taken place in Japan and the rapidly changing lifestyles of both younger and older generations, the percentage of elderly persons living in multi-generational households has been declining, from 37% in 1981 to 32% in 1991 and 22% in 2005 (Ogawa & Matsukura, 2005). Although the Government of Japan views the persistence of multigenerational households as an asset that can be tapped to offset the adverse effects of population ageing on the sustainability of the social security system, the validity of this view has increasingly been called into question in view of the trends observed (Ogawa & Matsukura, 2005).

Ogawa and Matsukura (2005) noted that because co-residence of elderly persons with younger relatives facilitates the exchange of resources between generations, the declining trend in the prevalence of multi-generational households has affected various aspects of the post-retirement lifestyle of elderly persons in Japan. One salient consequence as noted by Ogawa and Matsukura (2005) is the 211 changing trend in the place of death of older persons. Ogawa and Matsukura (2005) posited that while in 1965, 86.5% of the deaths of all persons aged 65 or over occurred at home, by 2003, the number was just 13.5%. This figure is a striking difference showing that fewer family members are staying together with elderly persons, and also less willing to care for these elderly persons in the same home.

With these changes of lower familial support and the declining trend in the prevalence of multi-generational households with elderly persons, the development of home-based care in Japan by volunteers was one of the ways started to fill this gap in the 1990s. But it has lagged far behind that of the UK or Scandinavian countries. For example, the proportion of elderly people receiving help from volunteers who clean their homes is at 2% in Japan, compared with 13% in the UK and Sweden, and 4% in the USA (OECD, 1996). Due to the strong emphasis on family values and encouragement of self-help at the policy level, the stigmatization of use of social services provided by the government in Japan has been heightened (Ikegami, Fries, Takagi, Ikeda, & Ibe, 1994).

In many parts of Japan, the elderly with dementia are cared for by volunteers, who are not related to them. This ‘open home’ concept is not provided by the government but by volunteers. According to Hayashi (The Guardian, 2014), the open house “*Suzu-no-ya*” scheme is run by volunteers who offer local residents with dementia and their caregivers the weekly opportunity to access all-day care, including lunch and tea. Drop-in facilities also include informal advice and peer support for caregivers, backed up by a 24-hour caregiver telephone support line. The open house concept embraces normalisation through provisions of familiar, relaxed and friendly surroundings. The scheme takes place in volunteers' own houses, or in low cost, vacant rental houses.

As the cognitive functions of those with dementia deteriorate further, these individuals are cared for mainly by their daughters-in-law. However, with increased longevity, many of these daughters-in-law are also ageing (MHW, 1994) and some of them also require medical assistance. The percentage of elderly residing with their children has been decreasing, with more elderly people staying at home alone for longer. However, the proportion residing with their children is still higher than in the USA and UK (Gerdet, 1995; Ichien, 1996).

In the later stages, these elderly with severe dementia are generally placed in Special Homes for the Aged (SHAs), a welfare facility familiar to nursing homes (Nogami, 1996). The challenges faced by the Japanese government are almost similar to those of Singapore. Japan faces three challenges. They were: 1) a rapidly ageing society, 2) lack of resources to provide long-term care, and 3) lack of a system for targeting their limited resources to care for the elderly with dementia (Arai, 1996). The Japanese government concluded that the ageing society is unavoidable. They have launched a ten-year strategy, the "Gold Plan", to target the second challenge of providing long-term care for the elderly with dementia (MHW, 1992). This Gold Plan aims to provide long term care (LTC) infrastructure, such as provision of in-home helpers, respite care beds, and day care centres. In addition to the Gold Plan, which was later revised into the "New Gold Plan" (MHW, 1995), a new public LTC insurance ("Kaigo Hoken") was legislated in 1997. This LTC insurance, which is financed by premiums and tax revenues, will pay for long term institutional care and home-based care for elderly dementia who are 65 years and above. The third challenge of providing a system to target the limited resources to help the elderly with dementia is still the most difficult for the Japanese government. Currently, geriatrics is not established as a discipline in the field of medicine in many Universities in Japan (Orima, 1998). Of the 80 medical schools in Japan, only 10 have a specialist geriatric department (Chugai, 1997). Hence, it is very difficult to provide a system to streamline the limited resources to help the elderly with dementia.

The case of Turkey

Turkey is a young country with more than half of its population under the age of 30 years old (Population Pyramid, 2016). However, 6% of the population was older than 65 in 2005, approximately 4 - 5 million people. The percentage of the elderly is expected to double by 2020 (Cankurtaran & Eker, 2007).

Alzheimer Europe (2014) estimated the number of PWD in Turkey in 2012 at 331,512. This represented 0.44 % of the total population of 74,508,771. Based on the total population of 78,665,000 in 2015 for Turkey (Population Pyramid, 2016), the number of PWD is estimated at 0.46% of the total population in 2015. The number of PWD as a percentage of the population is considerably lower than the European Union (EU) average of 1.55% (Alzheimer Europe, 2014).

Formal care for the elderly in Turkey is very limited. Traditionally in Turkey, the elderly either stay in their homes with their spouses or live with their children. For instance, 63% of elderly people live in their own homes, while 36% stay with their children. Only 1% live in residential care facilities (Atalay, Kontas, Beyazit, & Madenoglu, 1992). This stems from the accepted Turkish cultural norm that caring for the elderly at home is preferred (Bilgili & Kubilay, 2003).

The Turkish people show great respect to their elders (Birbiri, 2010). Sending an elderly parent to a nursing home is not a common practice in Turkey. Traditionally, Turks believe that treating the elderly well is a must. If an elder is not taken care of by his or her children, then neighbours and the community often take care of them. People over age 65, who have no income at all, are paid a monthly salary by the state. They are also treated free of charge at state hospitals. Also, Turkish Airlines, the railroads and many other organizations apply reduced prices for the elderly. There are a few nursing homes in Turkey, mostly state run. Some elderly people go voluntarily to these nursing homes. Most of the big cities have nursing homes as well. Those homes are run by municipalities and many volunteers work there. Companies sponsor or support these nursing homes. The poor elderly who have no income and no relatives are accepted into these nursing homes (Birbiri, 2010).

The level of care and degree of medical resource use in Turkey becomes progressively more intense as the patient's cognitive function declines. In later stages, patients are typically institutionalized, resulting in a greater proportion of formal costs (Meek, Mckeithan & Schumock*,* 1998). However, due to lack of services, such as adult day centres or residential care facilities in Turkey, in combination with transportation difficulties (as many of the elderly with dementia stay in rural areas), patients mainly have to remain at home under the supervision of their family-member caregivers, regardless of the stage of the disease. Therefore, indirect costs form the main contributor to the total costs in every stage of the disease. Zencir and colleagues (2005) examined costs at varying stages of dementia, and noted that the proportion of indirect to direct cost increased according to the severity of AD (Zencir et al.*,* 2005). Specifically, the proportion of informal cost of the total cost in the mild group was only 8%; however, this increased to 50% of total costs in the severe group. This finding is in agreement with the findings of a study from Israel which found that approximately 60% of the total cost was informal costs for elderly with severe dementia (Beeri, Werner, Davidson, & Noy, 2002). This could reflect the shifting status of the Turkish economy from a developing economy to a developed economy, with a shift in family's obligations as well.

The case of the United States of America

Dementia affects a large and growing number of elderly in the USA. The estimated prevalence of dementia for elderly who were 70 years of age and above in the USA in 2010 was 14.7% (Hurd, Martorell, Delavande, Mullen, & Langa, 2013). In a study by Moore, Zhu and Clipp (2001), the annual cost of providing informal care to elderly with dementia was estimated at US$18,385 per patient in 1998. The larger components of this cost comprised informal caregiving time (US$6,295) and caregiver's lost earnings (US$10,709). The aspects of cost increased with disease severity. This figure has increased over the years. The annual cost of dementia was noted either US$56,290 at 95% CIs [US$42,746, US$69,834] or US$41,689 at 95% CIs [US$31,017, US$52,362], depending on the methods used to value informal care (Hurd *et al.*, 2013). There are currently an estimated 5.3 million Americans with Alzheimer's disease in 2015 (Alzheimer's Disease Association, USA, 2016). There are 1.65% of PWD in USA based on a population size of 321.77 million in 2015 (Population Pyramid, 2016).

Comparing the three countries with Singapore, Japan (4.11%) has the highest percentage of PWD in 2015 based on population, followed by USA (1.65%) and Turkey (0.46%). Singapore has 0.72% of the PWD in the total population.

Care Services for the Elderly (PWD & PWOD)

Respite care for PWD in United States of America and Singapore

According to World Health Organization report (2015), respite care mostly occurs in elderly homes, but it can also be provided at DCCs or RCFs. Within these group settings, PWDs are able to interact in a safe environment with others who share similar problems.

In HIC such as the United States, DCCs and the provision of short-term respite care in RCFs were developed to aid PWD and their informal caregivers. Respite care facilities include one or more days of respite each week or respite for up to several weeks to enable family members, who act as caregivers, to take a break while the PWD stays in a supervised and safe environment. This arrangement contributes to the ultimate aims of supporting ageing in place for PWD. It also ensures that they receive high-quality care, and reduce the likelihood of health problems in family caregivers.

DDCCs and DCCs for PWD have been developed in Singapore. The Alzheimer’s Disease Association, Singapore, established four centres in publicly funded housing estate in 1990. The purpose of these centres is to take care of PWD and elderly who are recovering from strokes. These centres open for five days a week (Monday to Friday) and also on certain Saturdays. Transport is available upon request. Some of the activities include occupational therapy encompassing physical, cognitive and social domains, art therapy, and planned outings. One centre also serves as a day rehabilitation centre, and has a physiotherapist on the staff. Support groups are offered for caregivers, and those who require counseling. PWD who required additional respite care are referred to designated social workers. The centres are funded by the Ministry of Health through subsidies given to PWD who qualify through means testing (Alzheimer’s Disease Association, Singapore, 2016). These

DDCCs and DCCs are possible hybrids to aid and manage the transition for PWD from HC (Home Care), either with or without FDWs, to full - time RCFs. As noted by Tew et al. (2010), caregivers would mainly place their loved ones with dementia in RCFs as a last resort, where they have no financial means to employ FDWs to care for them at home.

In Chapter Three, a detailed study will be covered in Singapore on the analysis of FDWs, DCCs, DDCCs and RCFs on the impact of informal cost of care (by severity of disease).

Home-health and social-care system for PWD in Turkey

Turkey's Ministry of Health provides health care at home to support PWD and PWOD who are staying at home (World Health Organization, 2015). These services are provided free of charge and funded through a mix of expenditures from the general budget, taxes, municipal budgets and premiums paid by employers and employees. These services include home health care, psychological support, home repairs and maintenance, help with housework, personal care and cooking, and social activities offered by multidisciplinary teams of professionals (Ministry of Family and Social Policies, 2014). In 2015, the Ministries of Health, Family and Social Policies and the Interior, and the Union of Municipalities of Turkey instituted a new protocol that called for electronic data sharing among the various institutions and organizations providing home care for the elderly staying at home (Ministry of Health, 2015). The pilot system will start firstly in nine provinces, with the ultimate aim of countrywide implementation. The government will use data-sharing software to help ensure that older people receive home health care, social support and any other public services that they need. Data integration will also enable the delivery of a holistic coordinated approach, thereby improving efficiency and reducing the duplication of services. In the event when an elderly person or a family applies for a specific service, the information will be entered in the database. If someone is found to benefit from this service, they will notify the relevant institution via the database.

This protocol is a good example of how a country can enhance the delivery of comprehensive and integrated long term care, which includes health care and social care and support (World Health Organization, 2015).

Financing long-term care and other social programs in Japan

Long Term insurance plan. In 2000, Japan's government introduced an insurance long term plan to meet the needs of the elderly with the objectives of reducing the burden on family caregivers and integrating health care and welfare services into a comprehensive plan for insured populations (Ogawa, 2004). Elderly using long-term care services contribute 10% towards the cost of care (there is a ceiling for low-income insured people), with the remaining benefits being funded equally by insurance contributions and tax revenues. The system provides a generous set of services, including community-based and residential care, as well as free choice of services and providers (Mitchell, Pigott & Shimizutani, 2008).

Under this mandatory long term care insurance scheme, every Japanese resident at the age of 40 pays a monthly insurance premium. They become eligible for a range of services, including daycare centers and meal delivery, when they turn 65, or get sick with an ageing-related disease. The idea is to help seniors live more independently, reduce the burden on family caregivers, and create a market of companies competing to provide the eligible services (Forbes, 2015).

This new insurance scheme prompted a substantial increase in access to professional long-term care, with the proportion of elderly aged 65 and older using community services rising from 39% in 1999 to 61% in 2001 (Hayashi, 2015).

Disparities emerged among different areas of the country as the local governments managed the system. This disparity prompted debate about how to encourage uniformity of access to services across the entire country (Simizutani & Inakura, 2007). Simizutani and Inakura (2007) noted that increases in providing access to care homes has been more modest because the government controls the supply of such services and the elderly are still required to pay part of the associated costs. There had also been concerns that these payments may pose a significant access barrier to the elderly from poor families.

Flexible working schedules. While some companies in Japan create workplace policies hostile to employees who must take time off to care for elders, others do the opposite. Under the law (Japan External Trade Organisation, 2016), a worker can take up to 93 days off to care for a relative who becomes ill or is injured, with employment insurance covering 40% of their salaries. One healthcare company, Takeda Pharmaceutical, offers employees up to a year of nursing leave (Nikkei Asian Review, 2015). The clothes retailer, Uniqlo, offers a work week of four 10-hour days, designed for workers to spend time on child-rearing and nursing care (The Japan Times, Aug 2015).

Dementia-care training. Hospitals are finding it challenging to deal with the increasing number of dementia elderly who might wander about, remove their tubes or needles, or cause trouble with other patients. Nurses and healthcare workers are normally exhausted as they struggle to keep up with the PWD. The government initiated dementia training programmes for physicians and nurses, and hopes to have 87,000 people participating in them by the end of 2017 (The Japan Times, Mar 2015).

Driver-screening programmes. Of the approximately 470 fatal accidents caused by drivers aged 75 and over in 2014, 38% involved a driver with some form of cognitive impairment. Under a revised law, people suspected of having dementia will need to provide a medical certificate that they are capable of driving (The Japan Times, Jun 2015).

Daycare centers. About 7% of the nation's over-65 population uses DCCs in 2015, which focus on keeping visitors active, both physically and mentally, through activities such as cooking or day trips (Quartz, 2015). Some serve as DCCs for kids, mixing the young and old (The Japan Times, Nov 2014) while others incorporate art therapy (The Japan Times, Mar 2015) for both the elderly and the kids. These DCCs are not solely for the elderly but a hybrid for both the old and young to mix together, a different concept from many global DCCs that cater either solely for elderly or for the young.

Short-term-stay offerings. The term "shokibo takino", in Japan, refers to an in-between option for family members who want to keep their loved ones with dementia at home but need the occasional break. Family caregivers can bring in relatives for stays of up to 30 nights (The Star, Nov 2015). This is similar to the concept of respite care practised in Singapore and USA.

Search-and-rescue programmes. These programmes are being tested in about 40 cities in Japan (The Star, Nov 2015) and involve teams of social workers and medical professionals looking for people who have dementia but have not yet been diagnosed with it. The teams attempt to sign people up for services offered under the long-term care insurance program. Japan hopes to have teams in every city by 2018.

Cooperation with stores. In the Osaka prefecture, which leads the nation in reported cases of dementia sufferers gone missing, four major convenience store chains agreed to function as "dementia supporters" to assist seniors who appear disoriented (Japan Today, 2015). The chains, which between them have about 3,500 stores in the prefecture, send store managers to training sessions on how to identify and assist dementia sufferers. They will also cooperate with a quasi-governmental patrol-and-watch network that shares data on missing elderly via emails and faxes.

Summary

This chapter concludes with a summary table comparing the features of healthcare models in three developed countries of Japan, USA, and Singapore (see Table 6). The models of healthcare in the three countries review vary because of demographic, geographic, cultural, social and economic differences amongst countries. The current model of healthcare for Singapore, which is the focus of this thesis, contains some elements of the Japan and USA models of care, but is not a fully-integrated model of healthcare. Singapore may emulate some features of international models of care, but not all.

Table 6

Comparison table of Healthcare models for Japan, USA, and Singapore

	Japan (WHO, 2012) Population (2015) = 126.57 million	USA (WHO, 2016) Population (2015) =321.77 million	Singapore (MOH, 2007) Population (2015) = 5.60 million
Primary Healthcare Services	✓ Provided by government and private professionals ✓ 8,670 public and private hospitals, 99,824 private and public clinics, 68,384 dental public and private clinics ✓ no 'family-doctor' system	✓ Provided by General Practitioners or Family Physicians at clinics ✓ First point of contact for patients ✓ Public and Private hospitals: 5,700 hospitals, 15,900 nursing homes, 2,900 inpatient mental health facilities, 11,000 home health agencies and hospices	✓ Provided by professionals, usually general practitioners, in polyclinics and private medical clinics within the community. ✓ First point of contact for patients. ✓ 18 polyclinics and 1,500 private medical clinics.
Hospital Services	✓ Medical insurance is divided into broader categories: the Employees' Health Insurance and the National Health Insurance, which is a	✓ HMO (Insurance) or Social Security ✓ Integrated Delivery System is a strategic link amongst physicians, hospitals, patients and insurers ✓ No central governing agency	✓ Public: Total 8 of which 6 are general hospitals, 1 women's and children's hospital, and 1 psychiatry hospital. ✓ Beds: 185 to 2,010 beds for 16 public hospitals and specialty

	community-based system. Membership in either of the schemes is a must.	✓ Technology driven delivery system focusing on acute care ✓ Access to health care services is dependent on insurance coverage	centres, 20 to 345 beds for 10 private hospitals. ✓ Wards accommodation subsidy at Public Hospitals: Heavy subsidy by government. 81% of the public hospitals' beds (class B2 and C) are heavily subsidized with the remaining 19% with lower subsidy at 20% for class B1 and no subsidy for A class wards.
Day care services	✓ Open home concept “Suzu-no-ya” ✓ Older patients mixed with young children ✓ Welfare institutions for those who need constant care, and facilities providing rehabilitation service	✓ Adult Medical Day care: Community-based program designed to meet the needs of functionally and/or cognitively impaired adults through an individualized plan of care. These structured and comprehensive programs provide a variety of health, social, and other related support services in a protective setting. ✓ Psychiatry Day Treatment Services	✓ VWOs- Specialist day care for PWD, dementia day care services, social day care services, respite care.
Home Care	✓ Home based services: include home medical care; Home Nursing Care; Palliative Home Care; Meals-On-Wheels; Escort / Transport Services; Home Personal Care and Therapeutic Group Homes.	✓ Home based services: include home medical care; Home Nursing Care; Palliative Home Care; Meals-On-Wheels; Escort / Transport Services; Home Personal Care and Therapeutic Group Homes.	✓ Home based services: include home medical care; Home Nursing Care; Palliative Home Care; Meals-On-Wheels; Escort / Transport Services; Home Personal Care
Residential services	✓ Special Homes for the Aged (SHAs) ✓ For patients who need supervision or assistance with their activities of daily living for day and night. ✓ Continuing care facilities for patients who required continued care ✓ Provided by private providers island-wide	✓ Assisted Living: Residential or facility-based programs that provide housing and supportive services to meet the needs of residents who need assistance with performing activities of daily living. ✓ Hospitals: Acute Care & Psychiatric Hospitals, Freestanding Medical Facilities, HMOs, Patient	✓ For patients who need supervision or assistance with their activities of daily living for day and night. ✓ Continuing care facilities for patients who required continued care ✓ Provided by private providers island-wide ✓ Different fees structure depending on period of stay and types of care

	✓ Different fees structure depending on period of stay and types of care	Safety, Prison Hospitals, Residential Treatment Centers. ✓ Mental Health: Group Homes for Adults with Mental Illness, Mental Health Vocational Programs, Mobile Treatment Services, Nurse Referral Agencies, Nursing Staff Agencies, Outpatient Mental Health Centres, Psychological Rehabilitation Programs, Psychiatry Rehabilitation Services for Minors, Partial Hospitalization Program, Residential Rehab. Programs, Residential Crisis Services, Respite Care Services, Therapeutic Nursery Programmes.	✓ Centre based services: include community rehabilitation services, ✓ Long term stay: comprise community hospitals, chronic sick hospitals, nursing homes, inpatient hospice care, sheltered home for ex-mentally ill

Chapter Three

Cost of Care of People with Dementia in Singapore

Introduction

Singapore is a multi-racial country in Southeast Asia, with a resident population of 3.90 million (Singapore Department of Statistics, 2015a) of which 74.3% are Chinese, 13.3% are Malays, 9.1% are Indians and 3.2% belong to other ethnic groups in 2015 (Singapore Department of Statistics, 2015b). The population of older adults (defined as persons aged 65 years and older) in Singapore has increased dramatically from 2.5% of the population in 1965 to 11.8% of the resident population in 2015 in Singapore (Singapore Department of Statistics, 2015c). With an ageing population, the number of elderly with dementia is expected to increase in Singapore.

Dementia is not just a medical problem, it is also a societal problem, where economic and financial resources will be utilised. This is one of the greatest challenges for Singapore society in the coming era.

Total cost of care is a sum of formal and informal costs. Formal costs comprise medical costs and non-medical costs, and may be calculated based on costs of health service use and medications. Informal care costs comprise time spent by the caregivers on patients with dementia and play a major role in the total care costs for people with chronic diseases, including for patients with dementia. One of the major components of informal care costs is time, specifically the time spent in caregiving, typically provided informally by an untrained family member. However, it is not easy to quantify this component due to different methods of valuations and estimations. In this study, the total cost of care for PWDs in Singapore will be quantified. In addition, the impact on costs of the presence of FDWs and of the severity of impairment will be explored.

Economic Evaluation Methods

Evaluation of costs provides an estimate of the economic impact of a given disease. There are many different theoretical approaches to measuring health economic costs. Costs may be formal (e.g., hospitalisation) or informal (e.g., time) and direct (medical cost) or indirect (aids and adaptations). Below are six basic forms of economic evaluation of health economic costs:

1. **Cost-of-illness analysis.** This analysis calculates all the direct and indirect costs of a particular illness (Ernst & Hay, 1994; Gray & Fenn, 1993). Its purpose is three-fold: 1) it provides an estimate on the economic impact to society by such a disease like dementia; 2) it alerts policy makers in advance to the importance of the problem and suggest interventions to slow down its effect, and 3) it can provide a baseline estimate of costs compared with the potential economic impact of a new drug to intervene in the illness.

Cost-of-illness studies are a helpful way to document the origins and extent of care burden in respect to specific diseases. They need the identification, measurement and valuation of all resources associated with a specific disease. The output, expressed in financial terms, is an estimate of the full burden of a specific illness to society (Rice, 2000). Cost of illness studies have been criticized for their methodology (Drummond, 1994) and their utility (Byford, Torgerson, & Raftery, 2000). However, they are useful in determining the burden of a disease and the cost distribution across budgets and different sectors of the community.

2. **Cost-benefit analysis.** In a cost benefit analysis, the focus is on the outputs. The outputs or benefits are expressed in money terms in order to make them

commensurate with the costs of the intervention. Early intervention will result in savings in other direct medical care costs and the production gains from an earlier return to work (indirect benefits). However, intangible benefits, like the patient feeling healthier, are difficult to measure in money terms.

3. **Cost-minimization analysis.** This involves direct costs which fall mainly on the health care sector, and also indirect costs. This approach is used by Drummond (1994) in a study where the cost implications of two or more alternatives are included. The effectiveness of a drug treatment has impact not only on costs but also on the quality of life of the patient. The problem is how improvements in quality of life can be incorporated in an economic evaluation. One option is the cost-consequence analysis.

4. **Cost-consequence analysis.** Here costs and outcome are presented separately. Instruments for measuring quality of life can be used at different points in time. Generic quality of life instruments like SF-36 or specific instruments for dementia can be used. This method gives information on costs as well as quality of life, but they cannot be integrated into one evaluation measure, which reflects efficiency. In order to do that, the outcome has to be expressed in a single measure. This is the case with the two methods detailed below.

5. **Cost-effectiveness analysis.** Instead of measuring outcome in money terms like the cost-benefit analysis, this method measures outputs in terms of health effects. Health effects due to the consumption of drugs like “cases successfully treated” or “years of life gained” are used in this analysis by Oster and Epstein (1987, p. 2385). This analysis produces a measure of efficiency in terms of the incremental cost effectiveness ratio.

6. Cost-utility analysis. Cost utility analysis is concerned with improving the quality and not quantity of life in terms of “years of life gained”, in the cost-effectiveness analysis. Therapies like cancer chemotherapy or hypertension treatment may result in slight reductions in the quality of life through various treatments, with the ultimate objective of extending life. In this method, life-years gained from treatment are adjusted by a series of utility weights or utils. These weights reflect the relative values which the patient places on the different states of health (Drummond, 1994). The most frequently used output measure in cost-utility analysis is quality adjusted life-year (QALY). But the construction of QALY is not straightforward in dementia. Although there are advantages in using cost-effectiveness and cost-utility analysis, there are problems with finding and calculating an appropriate outcome measure.

Measurements of informal care time

The major informal cost of care is caregiving time. This generally consists of the amount of time spent with the patient by the primary informal caregiver and can be quantified as actual or potential wages lost by the caregiver. However, the provision of this informal care is now gradually being shifted to more than one caregiver (Wimo et al., 2013). This shift has complicated the valuation of the caregiver’s time.

There are several methods that are used to value the price of informal care time. Two of the most common methods are opportunity and replacement cost approaches. Opportunity cost approach seeks to identify the opportunities forgone by the caregiver as a result of their caregiving responsibilities (Mauskopf & Mucha, 2011). This approach attempts to place a monetary value on the alternative time forgone if they were not taking care of the patient. In calculating the opportunity cost, different values are assigned to this time forgone. This depends on whether the alternative use of time spent caring for the patient is paid as employment or leisure time forgone. The price for labour or wages forgone is different for an employed caregiver compared to a retiree caregiver or a foreign domestic worker (FDW). If caregiver is a retiree, informal care time is valued with leisure time, as a percentage of work time usually between 25% and 33% (Shea, 2000).

Replacement cost approach calculates the time spent on caregiving at the labour market price of a close substitute. Informal care time is valued at the wage rate or market price of a professional caregiver (Berg & Spauwen, 2006). The replacement cost approach allows the division of informal care into several tasks. Thus, informal care time can be valued with different average wages, which can be based on the hourly rates for nurse's aides, cleaners, book-keepers, and social workers (Harrow, Tennstedt, & McKinlay, 1995).

In this study, the informal care cost was estimated by multiplying the informal care time and the type of caregiver by the "price of labour" (i.e., wages, based on government published wage data) when they are not taking care of the patients. To best reflect reality, the replacement cost approach is used for ADL and the opportunity cost approach for IADL.

The case of Singapore

Singapore has a unique system where live-in full time FDWs play an important role as additional caregivers for the patients. FDWs are foreigners employed as domestic helpers in Singapore. These FDWs main responsibilities are in taking care of the household chores for the family. The need for these FDWs has risen as more people work in Singapore and as a result of the low unemployment rate (1.9%; Ministry of Manpower, 2016); many household families require FDWs to take care of the household chores. These FDWs are mainly from the ASEAN countries of Indonesia, the Philippines, and recently, Myanmar and Vietnam. They are usually from poor villages in their home countries and work to repatriate the strong Singapore dollars back to their countries to support their families and children's education. Some countries actually actively encourage their female workers to migrate abroad for domestic work as their remittances from abroad offset the unemployment rates and increase the foreign exchange reserves of their home countries (Chuang, 2010).

In Singapore, FDWs are employed especially when the PWDs are not in a full time RCFs or attending DCCs (Chong et al., 2013). Hence, with a view to quantifying the cost of informal care for PWD in Singapore, a detailed analysis of caregiver time will be conducted and results will be compared with the formal cost of care here.

In this study, the primary aim is to quantify the total cost of time of informal caregivers for elderly with dementia in Singapore. This study will also calculate the formal cost of care for them. Data will be collected from caregivers regarding how much they pay from their or from PWD own resources for the services used directly for dementia-related care (e.g., medications, day care, transportation).

PWDs are typically either at a full time RCFs, or cared for at home (HC) by full time FDWs (known as *helpers),* with primary caregiver support, in Singapore. Some of PWDs may spend half a day at DCCs or DDCCs and be cared for by FDWs at night. It is a common practice here for households to employ full time live-in FDWs to care for elderly relatives with severe dementia at home. These FDWs often have dual roles of assisting with the household chores as well as taking care of the elderly with dementia. These FDWs are expected to provide full-time care for the elderly family members as part of their duties (Yeoh & Huang, 2010). In some cases, FDWs are the main or sole caregivers for these elderly with dementia, for example when the primary family caregiver also has health problems.

Therefore, the value of the informal cost of care will vary, as the hourly labour cost paid to a FDW is not similar to that of a family caregiver. The latter may be a retiree or a paid employee when they are not taking care of the elderly with dementia, and this difference has an impact on costs in terms of wages foregone due to the caregiving role. Based on Singapore Ministry of Manpower data (Ministry of Manpower, 2016), a paid employee is paid based on a standard 44 hours per week in Singapore. This is the base figure used to calculate lost earning capacity for caregivers. Additional hours will be considered as over-time, i.e., work in excess of the normal hours worked.

To date, the only published study of costs of dementia care in Singapore (Chong et al., 2013) examined costs of care in mild and moderate dementia in families with and without FDWs. They found that median total annual costs of informal care were SG$15,750 per patient/year with mild dementia and SG$33,408 per patient/year with moderate dementia. Over half (57.9%) of Chong's sample had paid FDWs to assist in caring for the patients. Chong and colleagues (2013) found that costs were higher for patients without paid FDWs. The total hours of informal care by primary caregivers doubled in patients with moderate dementia, compared to those with mild dementia. However, Chong et al. (2013) only looked at costs of care in mild and moderate dementia, and did not include severe cases of dementia.

Costs of service use in Singapore are typically low for the individual patient as the majority of the non-dementia medications and services are government subsidised. However, medication, salaries and other service costs such as facilities and equipment must still be considered as part of the total costs of care. The present chapter seeks to calculate and compare formal and informal costs across mild, moderate and severe dementia in Singapore. Also, the impact on costs of the presence of FDWs and of the severity of impairment will be explored.

Measuring costs

Several instruments are available for measuring costs, such as Caregivers Activities Time Survey (CATS; Clipp & Moore, 1995), Caregiver Activity Survey (CAS; Davis et al., 1997) and Resource Utilization in Dementia (RUD; Wimo et al., 1998) instruments. Of these, CATS and CAS do not assess systematically all the activities that can be part of informal care (Clipp and Moore, 1995; Davis et al., 1997). For example, CATS does not include walking, cooking and shopping, and CAS does not include bathing, toilet visits and housekeeping. In contrast, the RUD instrument systematically considers a wide range of activities of Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL) and caregiver supervision. This study, therefore, used the RUD instrument to quantify the informal caregiver time in this study.

This study adopts a cost of illness approach in the analysis of data. This analysis calculates all the direct and indirect costs of a particular illness (Ernst & Hay, 1994; Gray & Fenn, 1993). Its purpose is three-fold: 1) it provides an estimate on the economic impact to society by such a disease like dementia; 2) it alerts policy makers in advance to the importance of the problem and suggest interventions to slow down its effect, and 3) it can provide a baseline estimate of costs compared with the potential economic impact of a new drug to intervene in the illness.

Cost-of-illness studies are a helpful way to document the origins and extent of care burden in respect to specific diseases. They need the identification, measurement and valuation of all resources associated with a specific disease. The output, expressed in financial terms, is an estimate of the full burden of a specific illness to society (Rice, 2000). Cost of illness studies have been criticised for their methodology (Drummond, 1994) and their utility (Byford, Torgerson, & Raftery, 2000). However, they are useful in determining the burden of a disease and the cost distribution across budgets and different sectors of the community.

This study aims to quantify the informal care costs incurred through time spent in caregiving by the primary caregiver and the other caregiver (including FDWs) for individuals in Singapore with mild, moderate or severe dementia. As stated above, most people with dementia in Singapore reside at home and are cared for by family caregivers (Tew, et al., 2010). Chong (2013) provided some data on costs, which the current study aims to explore further. The hypothesis of this study is informal care cost in Singapore is higher than formal care cost. In addition, the impact on costs of the presence of FDWs and of the severity of impairment will be explored.

Method

Participants

There were 346 consecutive existing patients attending a follow up consultation with a psycho-geriatrician in a government funded public health institution (the Institute of Mental Health, Singapore) during a four-month period from August to December 2015. Of these, there were 59 patients diagnosed with dementia and thus eligible for this study. Four PWDs were approached but declined to participate while another four PWDs did not turn up for their follow-up appointments. The rest of the 287 patients came for treatment of other psychiatric illness such as schizophrenia, bipolar affective disorder, anxiety disorder and depression but did not have dementia. The final number of PWDs was 51 (see Figure 5). All of these patients were aged 65 years or above, thus no inclusion criterion related to age was required.

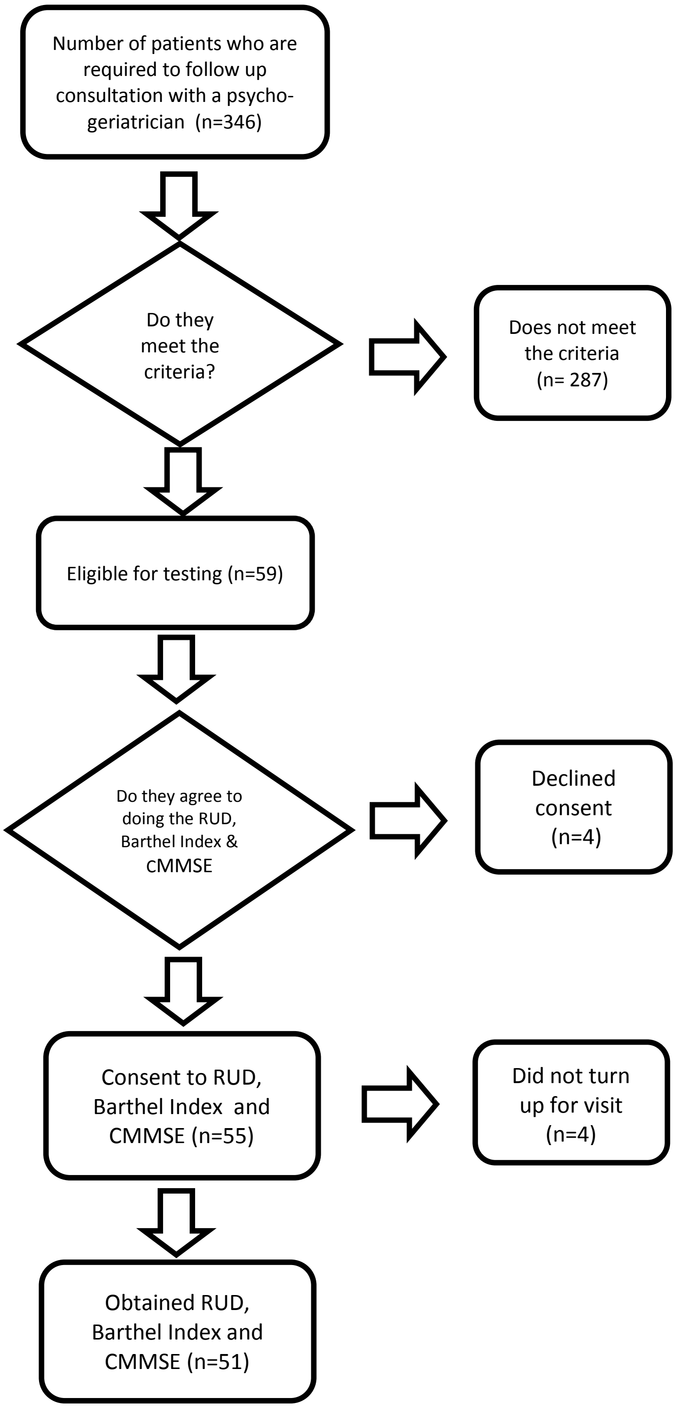

Figure 5. Sampling methodology for interview participants with dementia

This study included patients who met the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Text Revision (DSM-IV-TR) criteria for dementia. The inclusion criteria were all participants had to be accompanied by a reliable caregiver or other informant and be able to provide informed consent. They had adequate language skills and be fluent in English, Mandarin or Malay. The exclusive criteria included having other active psychiatric illness and no dementia; and significant physical, visual, and hearing impairment

There were 36 cases of Alzheimer's disease, 14 of vascular, and one of Lewy Body dementia. Participants had to be accompanied by a reliable caregiver or other informant and be fluent in either English or Mandarin. The sample included nine dementia patients from residential care facilities, four of whom were accompanied by nursing aides and five by the family-member primary caregivers. A cost of illness approach is used in this study.

Measures

Costs of care. The RUD was used to measure costs through a structured interview. Caregivers were asked to state the number of hours and days on a typical day they had assisted the patients in activities of daily living (ADL), instrumental ADL (IADL) and supervision during the last four weeks. This study assessed monthly informal care time based on time spent in assistance with (1) ADL, (2) IADL, and (3) casual supervision, for the patient with dementia at a single point of time in a month. Caregivers were also asked about their work status and hours of work lost due to caregiving.

Cognition screening. Data on dementia patients' general cognitive, abilities was collected using the Chinese Mini-Mental State Examination (CMMSE; Sahadevan, Tan, Tan, & Tan, 1997). The possible CMMSE score ranges from 0 to 28, with lower scores indicating more severe impairment (0-10: Severe, 11-20: Moderate and 21-24: Mild)

Function screening. The Barthel Index (Lubke, Mencke, & von Renteln-Kruse, 2004) is used to measure the functional capabilities of the patient, such as bowel and bladder continence, toilet use, bathing, feeding, grooming, dressing, mobility and ability to cope with stairs. The possible score ranges from 0 to 20, with zero indicating the greatest functional impairment. The Barthel Index score was divided into severe (0-9), moderate (10-15), and mild disability (16-20).

Valuations of formal cost: Formal cost is the sum of medical and non-medical costs. Medical costs are based on the cost of medications and health service used by patients with dementia. Non-medical costs include charges for DCCs, DDCCs, full time RCFs, cost of transportation, and costs of medical appliances such as heart pacemakers, incontinence pads, sheets, tubes, eye drops, and tissues for the patient. Caregivers were asked about medication and service use, and how much they paid from their own resources for expenses for services for PWDs. Direct medical costs were calculated based on the price of one unit of drug and the number of times taken per day for individual patients.

Valuation of informal cost: Informal costs are the sum of the opportunity cost of the time forgone by caregivers and FDWs, and hours of paid employment foregone by retired and semi-retired caregivers who would otherwise still be employed in the workforce.

Valuation of caregivers’ time is calculated for three subgroups of caregivers: employed people, retirees and domestic helpers. For employees, indirect costs are calculated in terms of productivity losses, i.e. missed days or part-days of paid work due to caregiving responsibilities. Cost-estimates are based on the median gross monthly income of full-time employed worker in Singapore in 2014, which was SG$3,770 (Singapore Department of Statistics, 2014). Time taken from paid employment was valued by using the 2014 census median income data from the Singapore Department of Statistics, where SG$21.42 represented the median wage earnings of the Singapore population, with an assumption of a 44- hour work week.

For retired caregivers, this study evaluated the time spent on caregiving (i.e., informal care) as indicated on the RUD. Daily hours of assistance with ADLs and IADLs was maximized at 8 hrs/day each and multiplied by SG$ 6.25 per hour as the base rate (based on the minimum salary of SG$1,000 in Singapore).

The cost of employing a live-in paid FDW, including fixed costs (administrative fees, agency fees, security bond, medical insurance, personal accident insurance, medical examination, cost of attending/settling in program) and variable cost (monthly food, basic necessities and lodging cost, foreign levy and gross monthly salary) was calculated with each caregiver individually and averaged to be SG$1,314 per month. FDWs typically work 96 hours per week or 384 hours per month (on 16 hour days with one day weekly off). This gives an hourly rate of SG$3.42.

For PWDs who did not use DCCs or DDCCs and use FDWs at home, and if FDWs were sole caregivers, compensation was at the same hourly rate for 16-hour day work on Sundays (off days for FDWs) to care for these patients.

For PWDs who use DCCs or DDCCs and use FDWs at home, FDWs will take care of them on Saturdays when these patients were at home. The primary caregivers will take care of these patients on FDWs’ off days (Sundays).

Procedures

Ethics approvals were obtained from the National Healthcare Group Domain-Specific Review Board, Institute of Mental Health Review Board and the James Cook

University Ethics Committee before any data was collected. Informed consent for the study was taken from the patient and caregiver. Caregivers were interviewed individually to complete the RUD and Barthel Index. Patients were simultaneously assessed with the CMMSE.

Results

Caregiver and patient characteristics at baseline

There were slightly more males (58.82%) than females with dementia. The mean age of the patients was 79.22 years (*SD* = 7.80). The mean ages of patients with mild (75.7), moderate (76.0) and severe (81.4) dementia are in Table 7. The majority (82.35%) of the 51 patients in this study had severe dementia with a handful having moderate (11.761%) and a few having mild (5.88%) dementia. Of the patients with severe dementia, the majority (69.05%) had Alzheimer's disease, more than a quarter (28.57%) had vascular dementia and one had dementia with Lewy bodies. The mean CMMSE score was 5.88 (*SD* = 5.87) and mean Barthel score was 7.82 (*SD* = 6.08). The majority of patients also had behavioural and psychological symptoms of dementia (BPSD). Most households (88.10%) had more than one primary caregiver and the majority (58.82%) also employed FDWs as additional caregivers to assist or substitute in providing care to the patient. Nine patients with severe dementia were in full time RCFs and all did not have FDWs.

The typical caregiver in this sample was 53.24 years (*SD* = 14.22), female (70.59 %). Almost half of the patients were taken care of by their adult children (41.18%) while more than a quarter (27.45%) was cared for by their spouses. The remaining patients were cared for by their sons or daughters-in-laws (9.80%), siblings (1.96%), FDWs (1.96%) or in full time RCFs (17.65%). The caregivers were relatively unhealthy with the majority (61.90%) taking medications and three quarters (75%) reporting more than one chronic condition.

Table 7

Baseline demographic details of patients

	Mild (*n*=3)	Moderate (*n*=6)	Severe (*n*= 42)
Cognitive status			
CMMSE	22.00 (1.73)	12.33 (1.51)	3.81 (3.47)
Functional status			
Barthel Index	12.67 (9.24)	10.33 (5.50)	7.79 (6.86)
Socioeconomic status			
Housing (%)			
1/2 -room public housing	0.00	16.67	2.38
3-room public housing	33.33	16.67	23.81
4-room public housing	33.33	33.33	33.33
5-room public housing	0.00	0.00	16.67
Private housing	33.33	33.33	2.38
Residential care facilities	0.00	0.00	21.43
Living arrangement (%)			
Own	33.33	0.00	4.67
Spouse/partner only	66.67	33.33	35.71
Sibling	0.00	0.00	4.67
Children	0.00	66.67	45.24
Foreign Domestic Worker	0.00	83.33	52.38
In laws	33.33	33.33	14.29
Residential care facilities	0.00	0.00	21.42
Top Six Other Chronic Health problems			
Hypertension	1.00	4.00	26.00
Hyperlipidemia	1.00	4.00	22.00
Ischemic heart disease	1.00	4.00	3.00
Diabetes mellitus	1.00	4.00	8.00
Benign prostatic hyperplasia	1.00	0.00	5.00
Anemia	0.00	1.00	5.00

Note: CMMSE maximum score = 28; Barthel Index maximum score = 20.

The most prevalent chronic conditions reported were hypertension (45.00%), osteoporosis (25.00%), hyperlipidaemia (25.00%) and diabetes mellitus (25.00%).

Other chronic conditions reported were depression, asthma, pain and anxiety (35.00%). The most commonly reported medications included antihypertensive agents (41.70%), medications for hyperlipidaemia (16.70%) and psychotropic medications (8.30 %).

ADL, IADL and Supervision

The mean number of hours that caregivers spent in assisting ADLs was 2.48 hours per day (*SD* = 3.32) and in assisting IADLs was 3.31 hours (*SD* = 2.90) per day (see Figures 6 and 7). However, this data was quite positively skewed, with the majority of caregivers reporting less than 4- hour assistance with ADLs (median = 1.5) and less than 4-hour assistance with IADLs (median = 3), with fewer caregivers providing more assistance. An additional mean of 2.36 hours per day (*SD* = 3.75) was spent on supervision of the patient (see Figure 8). The FDWs, rather than the primary caregivers, were usually responsible for most of the ADL, IADL and supervision of the patients. Time spent in assistance with ADLs was positively correlated with assistance with IADLs, $r = .60$, $p < .001$, and also positively correlated with time spent in supervising the patient, $r = .45$, $p = .003$. Time spent on IADLs and in supervision was also positively correlated, $r = .60$, $p < .001$.

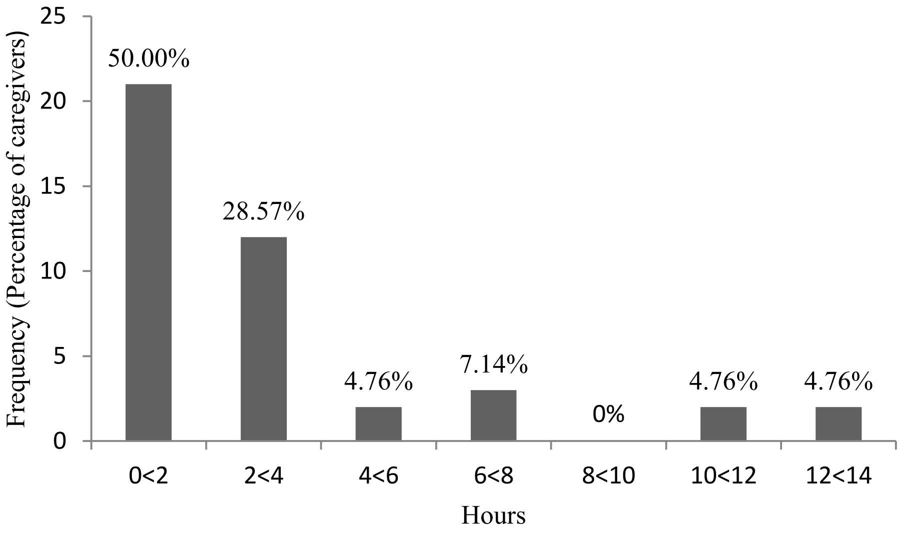

Figure 6. Distribution of hours per day that caregivers assist with ADLs

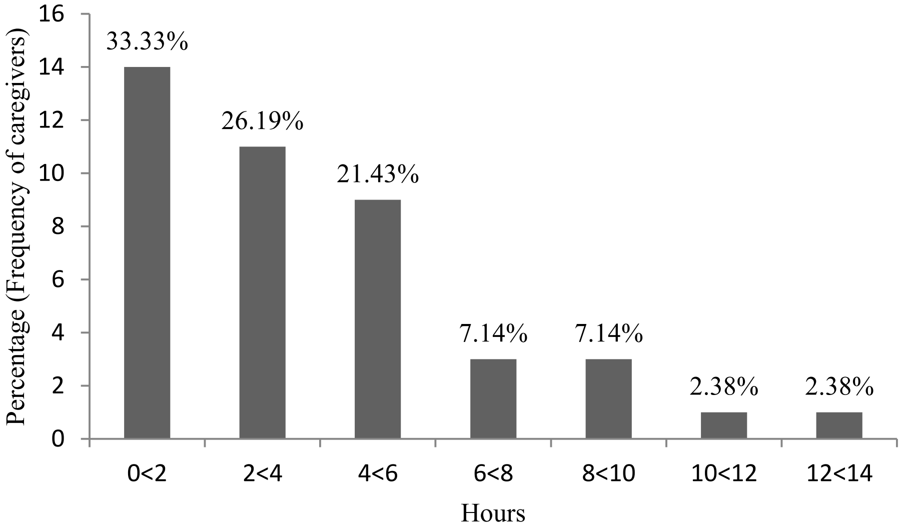

Figure 7. Distribution of hours per day that caregivers assist with IADLs

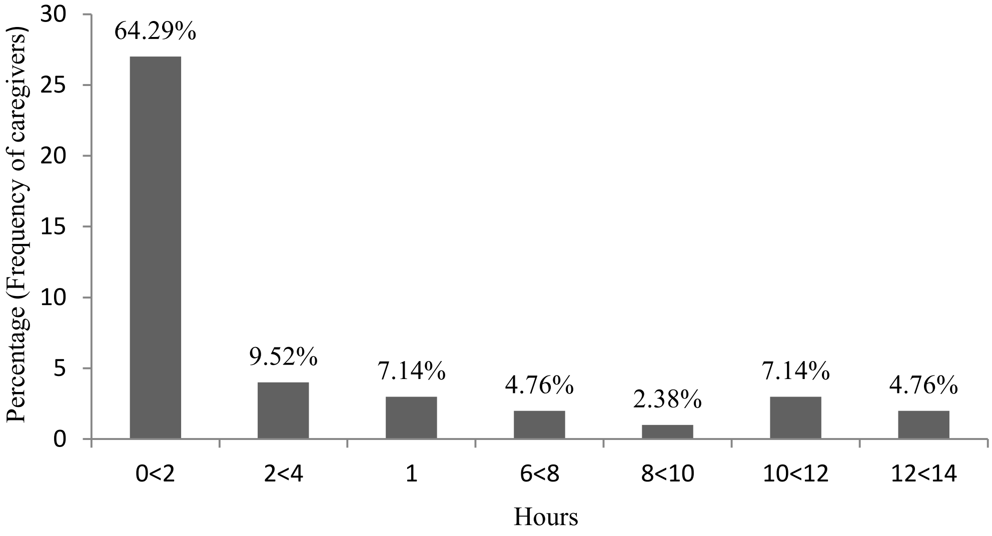

Figure 8. Distribution of hours per day that caregivers assist with Supervision

Healthcare Utilisation

A total of 13 patients (25.49%) were receiving drug therapy for dementia, including donepezil (*n* = 8), rivastigmine (*n* = 3), and memantine (*n* = 2). The mean number of other health problems reported for the PWD was 5 (*SD* = 2.73). The most prevalent other chronic conditions reported by these PWDs were hypertension (62.75%), hyperlipidemia (52.94%), diabetes mellitus (25.49%), ischemic heart disease (15.69%), benign prostatic hyperplasia (13.73%) and anemia (13.73%; Figure 9). The most commonly reported medications for patients with other chronic conditions included antipsychotics agents (48.4%), antihypertensive agents (31.3%) and medications for dyslipidemia (14.1%). Eight of the patients had been hospitalized in the previous month for stays of two to 30 nights (*M* = 8.65, *SD* = 9.35).

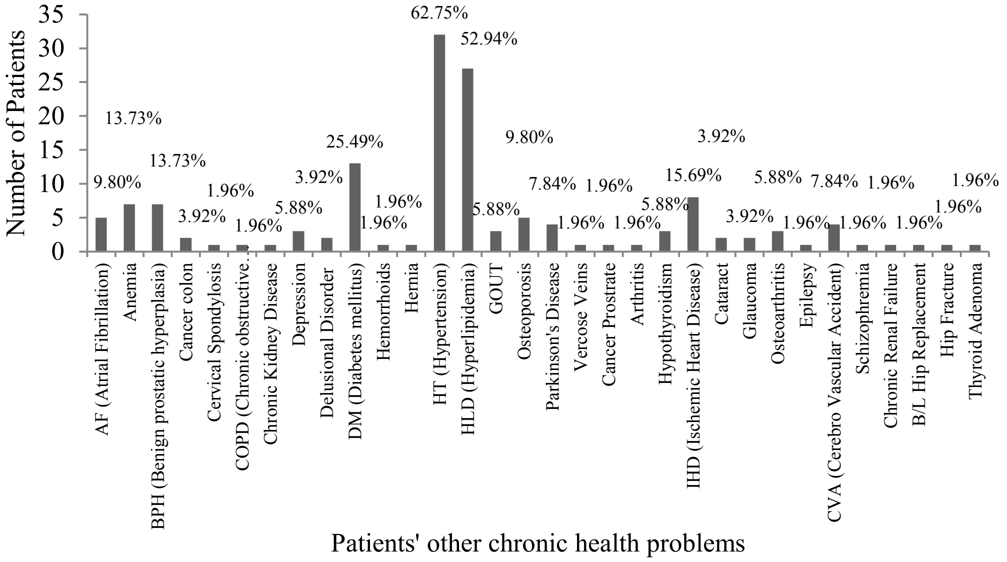

Figure 9. Patients’ other chronic health conditions

FDWs, DCC and RCFs

The majority of the patients (68.63%) were cared for full-time at home and the remainder were at full time RCFs (17.64%) and DCC (13.73%). Of those patients who were at home full time, most (74.29%) had a FDW in the household. FDWs will care for the patients on Saturdays, whereas on Sundays, which are the FDWs’ day off, the primary caregiver will take full care of the patient.

The patients who attended DCCs or DDCCs will typically stay at these centres for 8 hours per day (8:30 a.m. to 4:30 p.m.) five days per week. The DCCs or DDCCs provide transport to and from the caregivers’ homes.

All of the patients who were in full time RCFs had severe dementia and none had a live-in FDW at home.

Formal Cost of care

The mean monthly cost for dementia medications was SG$ 112.17 while the mean monthly cost of other non-dementia medication was SG$ 57.38 per patient. The mean monthly cost for dementia drugs was one of the top three highest formal costs of care (4.63%) for patients with dementia (see Figure 9). The mean monthly non-medication equipment cost (e.g. walking frames, pacemakers, continence management) for dementia patients was SG$84.20. The mean monthly charges for full time RCFs was SG$1,603.11 after subsidy (before subsidy SG$2,385.22). The mean monthly charge for DCCs or DDCCs was SG$326.27 after subsidy (before subsidy SG$960.00). The subsidy given by the government is dependent on many factors; some of these include the income level of the family, condition of the dementia patient and the type of accommodation. These full time RCFs costs were the most expensive in nominal terms of all the formal costs, constituting about 73% of the total formal costs (see Figure 10).

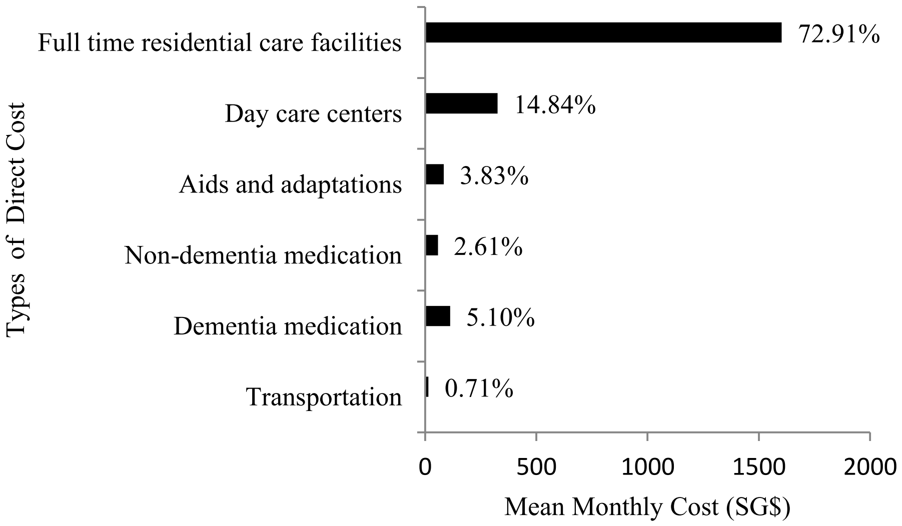

Figure 10. Components of Formal Direct Costs

Informal Cost of care

Informal costs are opportunity costs incurred by the caregiver due to taking care of the patient. For the employed caregiver who gives up work, this is the salary they forgo. The costs of FDWs are also included here. The community dwelling patients (*n* = 42) were divided into four groups based on DCCs used and FDW status for this analysis (see Table 8).

Table 8

Breakdown of patient's severity of dementia by type of care

	Residential care n (%)	Day centre n (%)	FDW n (%)	No other care n (%)	Total n (%)
Severity					
Mild	0 (0%)	0 (0%)	1 (3.85%)	2 (22.22%)	3 (5.88%)
Moderate	0 (0%)	0 (0%)	5 (19.23%)	1 (11.11%)	6 (11.76%)
Severe	9 (100%)	7 (100%)	20 (76.92%)	6 (66.67%)	42 (82.35%)
Total	9	7	26	9	51

1) **Patients who did not use DCCs or DDCCs or FDWs.** There were nine patients with dementia who were taken care of at home full time by primary caregivers and/or another caregiver. The median total annual cost of informal care of patients who stayed at home full time cared for by a primary caregiver and/or other caregiver was SG$18,473.28 for those with mild dementia, SG$37,800.00 those with moderate dementia and SG$83,674.08 for those with severe dementia (see Table 9).

2) Patients who did not use DCCs or DDCCs and with FDWs. There were 26 patients with dementia in our study who were taken care of at home full time with the aid of FDWs. Of these, one had mild dementia (with Lewy Bodies) and five had moderate dementia. The remaining 20 patients had severe dementia. The median total annual cost of informal care for these patients was SG$4,596.48, SG$38,769.41 and SG$37,287.07 for those patients with mild, moderate and severe dementia in Singapore, respectively.

There were altogether seven patients who used DCCs or DDCCs and all have severe dementia. They stayed at day care centres for 8 hours from Monday to Friday and stayed a home the rest of the time. While at home, other than the primary caregiver, these patients with dementia were taken care by either a FDW (*n* = 4) or by the primary caregiver and one other caregiver (*n* = 3).

3) Patients who use DCCs or DDCCs and with FDWs. There were 4 patients with severe dementia who were taken care of by FDWs when they were at home. The mean annual informal care cost with a primary caregiver and a FDW for these 4 patients was SG$32,114.88 per patient/year in severe dementia patients.

4) Patients who use day DCCs or DDCCs and without FDWs. There were three patients taken care of by the primary caregiver or other caregiver while at home. The median annual informal care cost with use of day care centres but without FDWs for these 3 patients was SG$77,984.80.

Employment status of caregivers for PWDs who use DCCs or DDCCs.

With FDWs. There were two patients (with severe dementia) who were being taken care of by retiree primary caregivers and FDW, whose monthly informal cost was SG$1,584.00, i.e. SG$19,008.00 annually. There were another two patients (with severe dementia) who were taken care by employed primary caregivers and FDWs, whose mean monthly informal cost was SG$3,768.48, i.e. SG$45,221.76 annually.

Without FDWs. There was one patient (with severe dementia) who was being taken care of by an employed primary caregiver and a retiree other caregiver. The monthly informal cost was SG$4,759.24, i.e. SG$57,110.88 annually. There were two other patients (with severe dementia) who were taken care of by an employed primary caregiver and an employed other caregiver. The mean monthly informal cost was SG$7,368.48, i.e. SG$88,421.76 annually.

Hence, the annual opportunity cost (SG$ 31,310.88) incurred by the employed primary caregiver and employed other caregiver without FDWs is 1.5 times that with one employed primary caregiver and a retiree other caregiver.

Table 9

Median total annual cost of informal care (SG$) of dementia patients

	With FDW (n)	Informal cost of care	Without FDW (n)	Informal care of costs
Did not use day care centres	Mild (1)	4,596.48	Mild (2)	18,473.28
	Moderate (5)	38,769.41	Moderate (1)	37,800.00
	Severe (20)	37,287.07	Severe (6)	83,674.08
Total	26		9	
Used day care centres				
	4 severe	32,114.88	3 severe	77,984.80
Total	4		3	

Relationships between informal care costs and disease severity

The median annual costs of informal care were SG$13,847.68 for patients with mild dementia, SG$38,607.84 for moderate dementia and SG$47,251.30 for severe dementia. Figure 11 shows a positive gradient between mean annual total cost of care and severity of dementia, indicating the mean total annual cost of care was the highest when the patients had severe dementia.

Relationships between informal care costs and functional capabilities

The mean total annual cost of care was highest when the patients had mild functional capabilities (see Figure 12). However, there was no significance association between informal cost of care and functional capabilities (see Table 13).

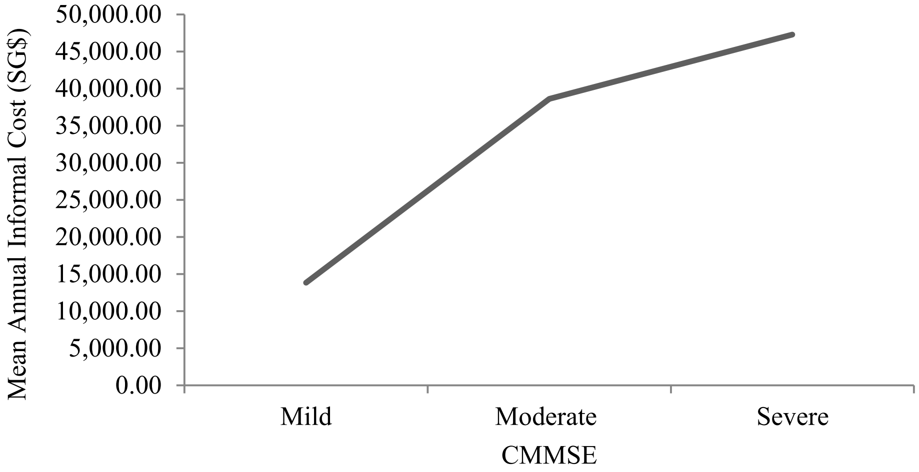

Figure 11. Relationship between Mean Annual Informal Cost and Disease Severity

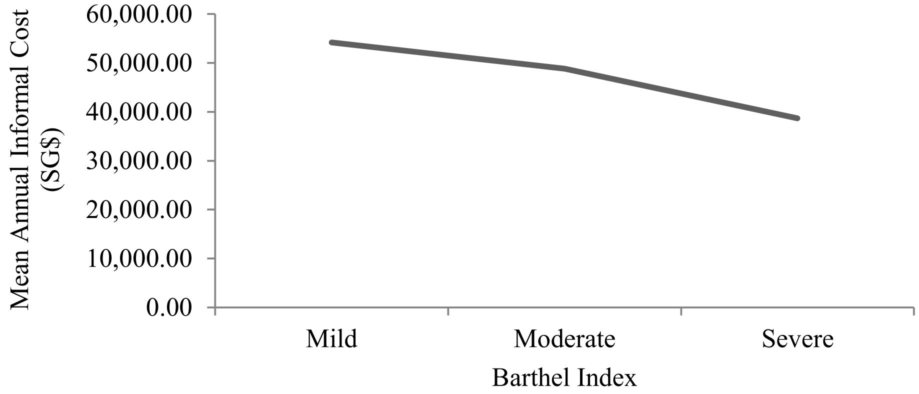

Figure 12. Relationship between Functional Capabilities Index and Mean Annual Informal Cost

Table 10

Cost Model on CMMSE and bscore

cost	CMMSE	cscore	bscore	bindex
19823.04	10	1	12	2
27204.48	8	1	7	1
57110.88	0	1	6	1
30464.64	11	2	11	2
46604.16	4	1	10	2

It is best to use full scores and not index values for analysis. The study models *cost* on *CMMSE* and *bscore* (see Table 10). A summary of the predictor values and response variable being modeled, i.e., cost in this case, are shown in Tables 11 and 12.

Table 11

Summary of Predictor Values

	Predictor Value			
	M	*SD*	*Min*	*Max*
CMMSE	6.45	6.15	0	24
bscore	8.64	6.02	0	18

Table 12

Summary of Response Variable Modelled

Variable	*N*	*M*	*SD*	*Min*	*Max*
cost	42	44530.55	31354.82	4596.48	129548.2

Table 13

Correlation of Both Predictors

	CMMSE	bscore
CMMSE	1.0000	
bscore	0.3541	1.0000

There is not much correlation between predictors (see Table 12), which is what this study wants for a model of cost on the predictors. The variable to be understood, or modeled, is cost. This study needs to determine if it normally distributed. Slight variations from normality are acceptable, but not substantial.

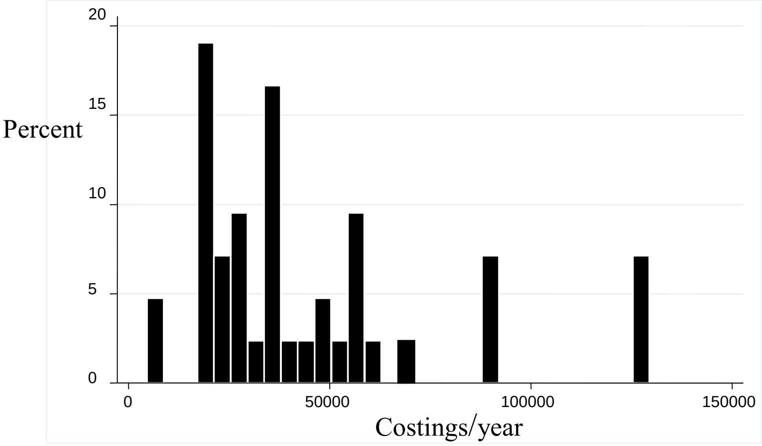

Figure 13. Distribution of Cost

As seen from Figure 13, cost is definitely right (positively) skewed. The *ladder* test on cost is used to indicate the appropriate transformation (see Table 14). Cost should be log transformed. This is demonstrated in the Table 14 which showed that a log transform is significantly preferable to leaving cost unadjusted. First, a standard regression with cost as unadjusted is demonstrated in Table 15.

Table 14

Ladder test on cost

Transformation	formula	chi2(2)	P(chi2)
cubic	cost^3	31.23	0.000
square	cost^2	25.34	0.000
identity	cost	13.14	0.001
square root	sqrt(cost)	4.80	0.090
log	log(cost)	2.72	0.256 ←
1/(square root)	1/sqrt(cost)	23.01	0.000
inverse	1/cost	42.52	0.000
1/square	1/(cost^2)	58.17	0.000
1/cubic	1/(cost^3)	61.86	0.000

Table 15

Regression of cost on CMMSE and Barthel Index Score

Linear regression	
N	42
F(2,39)	2.45
Prob > F	0.10
R-squared	0.06
Root MSE	31099
AIC Statistic	23.60
AIC*n	991.05

Table 16

Application of robust standard errors on cost model

cost	Coef.	Robust SE	t	P>|t|	[95% CI]	
CMMSE	-1173.94	575.45	-2.04	0.05	-2337.89	-9.99
bscore	1120.10	877.80	1.28	0.21	-655.42	2895.62
_cons	42424.40	7355.32	5.77	0.00	27546.86	57301.95

Note: CI= Confidence Intervals and SE = Standard Error

Table 17

Regression of log(cost) on CMMSE and Barthel Index Score

Linear regression	
N	42
F(2,39)	2.53
Prob > F	0.09
R-squared	0.12
Root MSE	0.67
AIC Statistic	2.10
AIC*n	88.22

Note: a log cost is done and remodeled the original model

Table 18

Application of robust standard errors on log (cost) transformed model

lcost	Coef.	Robust SE	t	P>|t|	[95% CI]	
CMMSE	-.04	.02	-2.14	0.04	-.08	-.01
bscore	.02	.02	0.90	0.37	-.02	.05
_cons	10.61	.19	56.79	0.00	10.23	10.99

```
. gen lcost = log(cost)
. reg lcost CMMSE bscore, vce(robust)
```

After the transformation of cost to log (cost), R squared raises from 0.064 to 0.124 (see Tables 15 & 17). Robust or sandwich standard errors have been applied which adjust the model for extra correlation in the data. The AIC goodness-of-fit test has been applied to both models, with the log-transformed model being a substantially better fit than the model with cost as the response (see Tables 16 & 18, Figure 14).

CMME significantly contributes to understanding the log of cost value (p=0.039) (See Table 18); *bscore* does not (p=0.373). The model concludes that with a one value increase in CMMSE scores, the log-cost will lower by -0.0429. The study can interpret the non-adjusted model better. CMMSE has a coefficient of -1173.939 and a p-value of 0.048. For each higher value of CMMSE, the cost lowers by 1173.94.

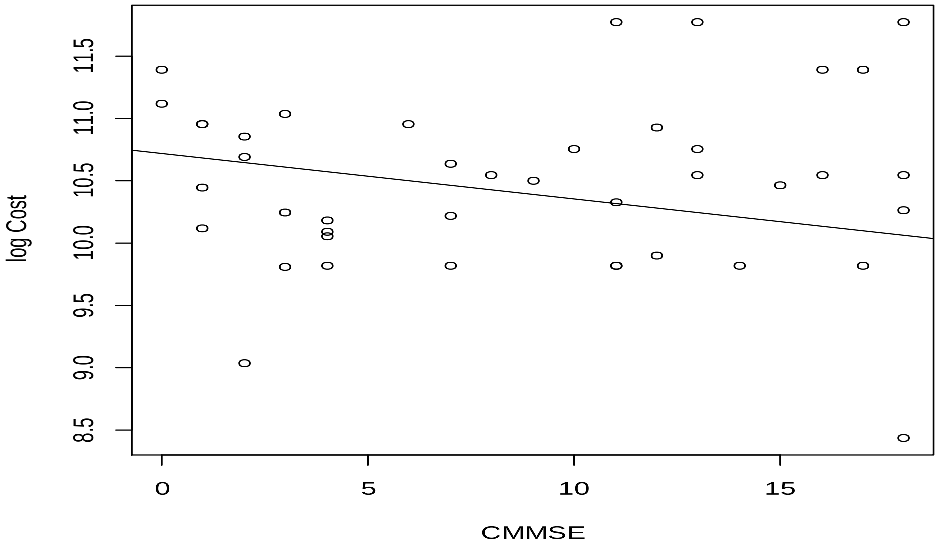

Figure 14. Transformation of Log (cost) and CMMSE

Total Costs

The total mean annual cost of dementia care was the sum of mean annual informal costs and formal costs, and totalled for this sample was SG$70,184.66. Of this total cost, SG$44,530.55 (63.454%) was attributable to informal cost of care and SG$25,654.11 (36.55%) was attributable to formal cost of care. Components of this total cost can be seen in Figure 15

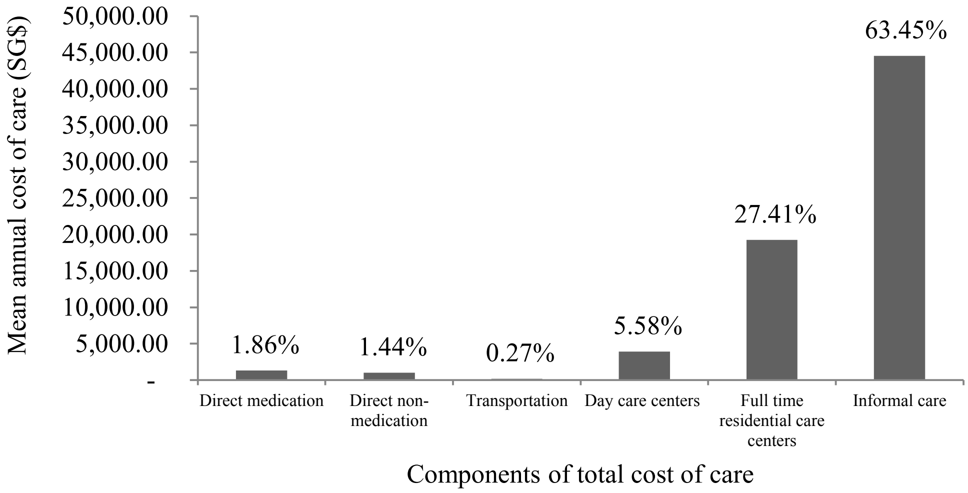

Figure 15. Annual Total Cost of Dementia in Singapore

Discussion

Valuing Informal Care and Time

This study aimed to quantify the informal care costs incurred through caregiving in Singapore and to explore differences in costs for patients with mild, moderate or severe dementia and with the use of alternative caregiving services of day care centres and FDWs. The mean annual total cost of informal care was SG$44,530.88 in our sample. Costs were found to increase with severity of dementia. The main components of caregiving measured were time spent in assisting with ADLs, with IADLs and in supervision, and these were all correlated, thus total time spent in caregiving is reflected in the increased costs at higher levels of severity of cognitive impairment.

Valuing Informal Care and Measuring cost with and without FDWs

The informal cost of care for those with dementia did not vary much with or without the use of day care centres, however, the costs for those who did not have FDWs was approximately more than double the costs for those with FDWs. Ceterius paribus, our results showed that there were cost savings in care of the patients with dementia when the family employed live-in FDWs. These findings were consistent for both patients with mild, moderate and severe dementia and for those who did or did not use day care centres. Families in Singapore often employ a full time live-in FDW, to reduce the burden of care by the primary caregiver and our data shown this is reflected in reduced costs of care where FDWs are employed. When the primary caregiver was unable to assist the patient with dementia, this time taken to care for the patient was commonly replaced by the FDW.

A very small proportion of this sample of patients was in RCFs, and this reflects the cultural tendency to keep patients at home as long as possible. This arises mainly due the Chinese cultural belief of filial piety where it is the responsibility of the children to care for their elderly parents (Yeoh & Huang, 2010). It seems likely that the presence of FDWs enables this approach to care by lessening the time and financial costs of keeping the patient at home.

Valuing Formal Care and Measuring Medication Cost

There were also some formal costs considered in this study. The mean annual cost of RCFs for nine severe patients was SG$19, 237.33. Medication costs for dementia-related medications were incurred by 25.49% of the sample, and non-dementia related medications for 74.51% of the sample. The actual costs of non-dementia medication reported by the caregivers was quite low (at a mean annual cost of SG$ 688.56), mainly because majority of these patients were on the civil service scheme in which costs of drugs were fully subsidised by the government, or are deducted from the patient’s Medisave medical account, hence there is no out of pocket expense. Medisave is a national medical savings scheme which helps Central Provident Funds (CPF) members put aside part of their income into their Medisave Accounts to meet their future personal or immediate family's hospitalization, day surgery and certain outpatient expenses (Central Provident Fund Board, 2016). Under this national savings scheme, CPF members contribute a part of their monthly salary to their Medisave Account (MA). If they are self-employed and earn a yearly Net Trade Income (NTI) of more than $6,000, they will also need to contribute to Medisave. The contribution and allocation rates to the MA are dependent on the age of the employee (Central Provident Fund Board, 2016).

In addition, Singapore has a Pioneer Generation scheme, which heavily subsidises services. The Government started a special Pioneer Generation Package in 2014, helping to foot the medical bill of elderly Singaporeans under the revamped national insurance scheme, MediShield Life (Pioneer Generation, 2016). The move ensures that this group of Singaporeans, described as being in their late 60s and above and who have worked hard to build a modern Singapore, will never have to worry about healthcare in their old age. About 450,000 Singaporeans in 2015 benefitted from the Pioneer Generation Package. The package helps Pioneers with their healthcare costs for life. The benefits include:

1. Outpatient care. Pioneers will receive additional 50% subsidies on top of existing subsidized services and medication at polyclinics & Specialist Outpatient Clinics. They also enjoy subsidies at participating General Practitioners (GP) and dental clinics under the Community Health Assist Scheme (CHAS; CHAS, 2016). CHAS enables Singapore Citizens from lower- and middle-income households to receive subsidies for medical and dental care at participating GPs and dental clinics near their homes.
2. Medisave Top-ups. Pioneers will receive Medisave top-ups in their Medisave Accounts annually for life.
3. MediShield Life. This scheme will support for all Pioneers' MediShield Life Premiums with special premium subsidies and Medisave top-ups. All Pioneers will pay fewer premiums for MediShield Life than Medishield.
4. Disability Assistance. There will be cash of SG$1,200 a year for those with moderate to severe functional disabilities under the Pioneer Generation Disability Assistance Scheme.

However, the cost of all the dementia medications here (i.e. donepezil, rivastigmine and memantine) are not subsidised by the government, which accounts for the high mean annual costs of these dementia drugs of SG$1,346.04. Some of these patients had behavioural and psychological symptoms in dementia, which are secondary to dementia; hence they were not on any medications and had no other chronic health problems. There were also other patients who were not on medications because these other chronic health problems (such as diabetes mellitus) are controlled by their diets and exercises.

Importantly, the costs of dementia drugs are currently not subsidised by the government in Singapore. These dementia drugs are costly and are currently one of the top three high costs for these patients. There are other patients who need these dementia drugs but are not prescribed because of the high cost. The government may consider channelling resources to partially subsidise these dementia drugs so that they are accessible to more patients from lower income levels that have dementia but cannot afford to buy them.

Informal Care Cost in Singapore

To date, the only other data of costs of informal care in Singapore is provided by Chong et al. (2013), who reported median annual costs of SG$15,750 for those with mild dementia and SG$33,408 for moderate dementia. This study showed quite similar costs, at SG$13,847.86 for mild dementia, and SG$38,607.84 for moderate dementia. However, this study has also estimated median annual costs of informal care for severe dementia, at SG$48,727.91, and further demonstrated that the informal costs of care rise with the severity of cognitive impairment, rather than functional impairment, of the patient. For each higher value of CMMSE, the informal cost lowers by SG$1,173.94.

Informal Care cost in Singapore vis-à-vis United States, Japan, United Kingdom and Turkey

Data from this study showed median annual informal cost of care at US$9,891.33, US$27,577.03 and US$34,805.65 for mild, moderate and severe dementia in Singapore which are comparable to those reported in the European and

US studies of US$10,802.38, US$19,983.66 and US$62,974.90 for mild, moderate and severe dementia respectively (Gustavsson *et al.,* 2010; Moore, Zhu & Clipp, 2001), in 2015 dollars. This is despite the prevalent of employment of FDWs in the provision of informal care of the patients when they were fully or partially staying at home.

At the 2015 International Conference on Cognitive Decline and its economic consequences in Japan, the informal care cost of dementia elderly in Japan was US$31,675.64 per person per annum. In a study by Moore, Zhu and Clipp (2001), the annual cost of providing informal care to elderly with dementia was estimated at US$26,733.48 per patient (in 2015 dollars) in the United States. The larger components of this cost were in informal caregiving time (US$9,155.56, in 2015 dollars) and caregiver's lost earnings (US$15,571.87, in 2015 dollars). The aspects of cost increased with disease severity. This figure has increased over the years. Hurd and colleagues (2013) noted that the annual cost of dementia in the United States was either US$56,290 at 95% CIs [US$42,746, US$69,834] or US$41,689 at 95% CIs [US$31,017, US$52,362], depending on the methods used to value informal care.

Table 19 showed the mean annual informal cost of care in 2015 at US$31,807.78 in Singapore is comparable to those in developed countries of the United States, US$49,843.29, in 2015 dollars (Hurd et al., 2013), United Kingdom, US$51,894.86, in 2015 dollars (Torjesen, 2014), and Japan, US$31,675.64 (International Conference on Cognitive Decline and Its Economic Consequences in Japan, 2015). Turkey, being a developing country, had a relatively low mean annual informal care cost of US$5,327 (Zencir *et al.,* 2005), in 2015 dollars compared to Japan, Singapore, United Kingdom and United States.

Table 19

Informal cost of care for PWD in USA, UK, Japan, Singapore and Turkey

Country	Mean annual informal cost of care for dementia (in 2015 US dollars)
Japan	31,675.64
Singapore	31,807.78
Turkey	5,327.00
United Kingdom	51,894.86
United States	49,843.29

Total Care Cost of Dementia in Singapore

There are currently about 40,000 people with dementia in Singapore (Alzheimer's Disease Association, Singapore, 2016), which is costing the government SG$2.81 billion annually. By 2030, that number is expected to rise to 92,000 (Alzheimer's Disease Association, Singapore, 2016), using the cost per person (per capita) estimate which is then multiplied by the number of people estimated to be living with dementia in that country. The study estimated that it will cost the government healthcare expenditure to escalate almost triple to SG$ 6.46 billion, of which SG$4.10 billion will be attributable to informal cost of care and SG$2.36 billion to formal cost of care for PWD in Singapore.

Limitations and Strengths

To the best of my knowledge, this was the first study that estimated the cost of formal and informal care of dementia in Singapore. However, the findings of this paper should be interpreted in the context of some limitations. First, the small sample size here is a limitation that may constraint the statistical power to build a model of costs and the generalizability of the results. However, the response rate of 92.73% is a strength and increases our confidence in the reliability of the data. Second, being a cross sectional study, the study is unable to determine if the current type of care for PWDs (i.e., cared by FDWs, DCCs, DDCCs or RCFs) will change over a period of time, depending on the progress of the disease. Third, the general nature of the result may be limited by the study sample size characteristics of the caregivers. This study sample was a selected population of caregivers who are educated and able to complete the questionnaires independently at the clinics. The subjects were more motivated caregivers who have been bringing the PWDs for regular check-ups with the geriatrician at the dementia clinic. Lastly, the participants in this sample were mainly Chinese Singaporeans. As Singapore is a multi-racial and cultural society and socio-cultural factors played an important role on the outcome related to dementia care, results of this sample study cannot be directly assumed and be extrapolated to other ethics groups in Singapore. This study used widely accepted, well validated assessments. The Resource Utilisation in Dementia (RUD) is arguably the most widely used and well-documented instrument for assessing informal care time. This sample was clinically recruited and systematically diagnosed using DSM criteria. Most previous studies only recruited patients living in the community, excluding patients living in full time residential care facilities. This approach is likely to underestimate total costs of care as well as relationship between disease severity and care costs as the risk of full time residential care facilities increases with severity. This study has included an estimation of the cost for patients who are in full time residential care facilities. This study also quantified the cost of care according to the severity of dementia, and also specifically quantified the impact of FDWs on the cost of care for these patients. Therefore, this study provides novel and useful insights into the costs of dementia care in Singapore.

Recommendations for Future Studies

This study did not consider caregivers' sleeping time as supervision and implicitly assumed that caregivers did not supervise during sleep. Hence, there was a possible underestimate of supervision time in this area. However, the practice of employing night workers to take care of the dementia patients at night is rarely practised in Singapore and was not applicable to this sample. Secondly, PWDs are likely to have more co-existing chronic health problems than those without dementia, because they tend to be older and because certain diseases (e.g., stroke and depression) are more common in persons with dementia (Barnes & Yaffe, 2011). Thus, adjusting for the presence of these co-existing conditions is important in estimating the costs due to dementia alone. Thirdly, this study assessed disease severity using appropriate standard instruments for cognition and ADL function, however this study would recommend further research also include a measure of behavioural and psychological symptoms of dementia. Finally, as noted above, the sample size was small. Ideally, future research could collaborate across institutions to gather a larger sample of people with all stages of dementia and their caregivers.

Conclusion

The study main findings were: 1) the mean annual cost of informal care in Singapore was 1.7 times higher than cost of formal care; 2) the mean annual informal cost of care was 2.3 times higher than full time cost in RCFs; 3) the formal cost of care was highest for PWDs in RCFs, DCCs or DDCCs and the cost of dementia medication; 4) the annual costs of informal dementia care increased with disease severity; 5) for each higher value of CMMSE, the cost lowers by SG$1,173.94; 6) there was no significant association between annual cost of informal care and functional abilities; 7) the mean annual informal cost of care in Singapore is comparable with those in developed countries like the United States, United Kingdom and Japan; 8) the informal cost of care for those with dementia did not vary much with or without the use of DCCs or DDCCs, 9) the costs for those who did not have FDWs was more than twice the costs for those with FDWs; 10) PWDs also suffered from an average of 5 other chronic health conditions; 11) the most common chronic conditions reported by these PWDs were hypertension, hyperlipidemia, diabetes mellitus and ischemic heart disease; and 12) the most commonly reported medications for patients with other chronic conditions included antipsychotics agents, antihypertensive agents and medications for dyslipidemia.

The number of PWD is rising rapidly worldwide due to higher life expectancy. Like the rest of the world, Singapore is an ageing society. This will place substantial additional pressure on publicly-funded health, long-term and income support programmes for elderly people. In the long term, the informal cost of care in Singapore is likely to be shifted to the formal cost of full time RCFs when the cognition and function of these PWDs deteriorates further. Thus the cost will be transferred from caregivers to society. Transition from full HC or partial HC and DDCCs, DCCs into RCFs will only increase total costs of dementia care from a societal perspective. Nobody benefits in this situation. Hence, it is crucial that policymakers allocate resources (monetary and non-monetary) effectively to caregivers.

Chapter Four

Costs of Care of People without Dementia in Singapore

Introduction

The purpose of this chapter is firstly in Study 1, to evaluate the costs of care of PWOD, and secondly in Study 2, to compare these costs with PWD in Singapore reported in Chapter three. The aim is to increase the utility of the data from Chapter three by providing a comparison of data on costs of care of PWD and PWOD in Singapore.

As the population of older people grows, health care costs are expected to escalate enormously, even with no real change in the health status of older people. Governments and health care providers in many countries are concerned on ageing populations because of the high health care costs incurred by them.

In the USA for example, based on Centers for Medicare and Medicaid Services, USA (2016), a person personal health care spending for the 65 and older population was US$18,424 in 2010, which was 5 times higher than spending per child (US$3,628) and 3 times spending per working-age person (US$6,125). The elderly was the smallest population group at 13 percent of the population and accounted for the remaining 34 percent of spending in 2010.

Factors affecting elderly healthcare expenditure

United States of America. Medicare costs for the oldest old (those aged 85 and above) may increase six-fold by the year 2040 (Schneider and Guralnik, 1990). A study by Wiener and Tilly (2002) showed similar conclusions. Between 2000 and 2050, the number of older people is projected to increase by 135%. Moreover, the population aged 85 and over, which is the group most likely to need health and long-term care services, is projected to increase by 350%. Over this time period, the proportion of the population that is over the age of 65 will increase from 12.7% in 2000 to 20.3% in 2050; the proportion of the population that is age 85 and older will increase from 1.6% in 2000 to 4.8% in 2050. This highlights the importance of measuring costs of care for older people.

However, Newhouse (1992) posited that the US had been spending too much of healthcare expenditure, exceeding 12% of GNP in 1990, suggesting the increase is due to advances in technology rather than the ageing population. Newhouse (1992) concluded that neither the direct nor indirect effects of ageing on expenditure appear to account for much of the sustained rise in medical expenditure in the USA. Study by the National Research Council, USA, (2010) showed increased healthcare expenditure in the US. The United States spent $2.2 trillion in 2007 or US$7,421 per person on medical care, which accounted for 16.2 percent of the gross domestic product (GDP) for the year. As a proportion of GDP, medical care spending in the United States substantially exceeds that of other industrialized countries: among all Organization for Economic Co-operation and Development (OECD) countries, the median proportion is 8.5 percent (National Research Council, USA, 2010). However, based on the National Research Council, USA, (2010), the high healthcare expenditure is driven by non-medical factors like diet, exercise and environment. These determinants affected healthcare costs of the ageing population and the elderly health status.

Aside from chronological age, an individual’s level of function may be an important determinant of their healthcare costs. Lubitz, Cai, Kramarow and Lentzner (2003) found that an elderly person who resides in the USA without functional limitation at the age of 70 years had a higher life expectancy and lower expected cumulative care expenditure than an individual of the same age with a limitation in at least one activity of daily living (ADL). Specifically, a person with no functional limitation at 70 years of age had a life expectancy of 14.3 years and expected cumulative health care expenditures of about US$197,756.52 (in 2015 dollars); a person with a limitation in at least one ADL had a life expectancy of 11.6 years and expected cumulative expenditures of about US$210,843.34 (in 2015 dollars). Similarly, persons who were institutionalized at the age of 70 had cumulative expenditures that were significantly higher than those for persons who were not institutionalized (Lubitz et al., 2003). However, there is increasing evidence that these costs are more closely related to proximity to death (number of years left to live) than to current chronological age (Mcgrail et al., 2000). This means that studies with projections using age-specific costs will exaggerate the impact of ageing as relevant cohort effects (such as cost-saving advances in medical care) are not taken into account.

A limitation of previous studies of the relationship of age, proximity to death and costs is the tendency to restrict the analysis to acute medical care, without considering nursing and social care. It is important to take into account the relatively large impact of ageing on social and nursing care (Mcgrail et al., 2000). While studies of proximity to death are by nature lengthy, expensive longitudinal studies, the impact of ageing on costs of care is relatively straightforward to evaluate. Therefore, in the same way those costs of care in dementia are often considered in relation to age, data is needed that considers costs of healthcare in relation to age for PWOD.

Sweden. Nordberg et al. (2007) examined costs of residential care in Sweden for participants in residential care facilities and found there is a variation in nurses and nursing aides’ time use due to differences in ADL dependency and the presence of dementia. That study used the RUD to demonstrate that this variation in time use has implications for costs of residential care. However, that study was limited to participants in residential care. For my purpose, this study required data on community dwelling individuals in order to provide a comparison for the participants with dementia in Chapter Three.

United Kingdom. Snell (1985) examined the costs of care of elderly persons in the UK who live in their own homes (i.e. community dwelling) as compared to those in residential homes, to ascertain whether the level of dependency did significantly affect the costs of care. The study found that variations in the average costs of care were significantly explained by both cognitive and functional status of the elderly person. Snell (1985) also noted that the gender and residential status of the elderly were important factors in relation to costs. Snell (1985) found that very few elderly people who were community - dwelling had a total cost of care greater than the average cost found in residential care facilities. Snell (1985) posited that even with very high levels of cognitive and functional disability of the elderly persons, the costs of care in the community dwelling for those living alone were still lower than residential care costs.

With regards to gender, Snell (1985) noted that services were provided to different levels for males and females even if they were of similar physical and mental disability, however Snell did not elaborate on the costs involved in providing these services.

Japan. In a study by Kato, Tamiya, Kashiwagi, Sato and Takahashi (2009) on a relationship between home care service use and changes in the care needs level of Japanese elderly, the team noted that for the lower care needs subgroup (less severe cognitive impairment or mild dementia subgroup), age, use of respite stay in a nursing home and the number of types of long-term services are important determinants on the elderly care needs in Japan. However, for the higher care needs level community-dwelling elderly persons, the main determinant was the medical management by a physician service which was related the elderly care needs.

Europe. Some studies have reported positive effects of home care services including reductions in functional decline (Gitlin et al., 2006; Beswick et al., 2008), mortality rates (Kono, Kanagawa, Ban, Kitahama, & Matubara, 2002; Kuzuya et al., 2006) institutionalization rates (Stuck, Egger, Hammer, Minder & Beck, 2002; Beswick et al., 2008; Elkan et al., 2001; Vass, Avlund, Hendtiksen, Andersen & Keiding, 2002) and costs of care (Weissert, Lesnick, Musliner & Foley, 1997). Other studies, however, have reported that home care services are ineffective in reducing functional decline (Stuck et al., 2002), mortality rates (Bouman et al., 2008) and institutionalization rates (Huss et al., 2008; Bouman et al., 2008; van Haastregt, Diederiks, van Rossum, de White & Crebolder, 2000) in community-dwelling elderly persons.

In these studies, home care services consisted of home help, home bathing services, a visiting nurse, home rehabilitation, nursing home daycare, health daycare, loan of medical devices, respite stay in a nursing home, respite stay in a health care facility, respite stay in a sanatorium-type medical care facility, and medical management by a physician.

Over the years, there has been inconsistent evidence that the residence status of elderly who own homes (community dwelling) or stayed at DCCs, DDCCs or respite care facilities as compared to those in RCFs would experience improvement in their cognitive impairment, hence reducing the costs of care.

Canada. Forget, Roos, Deber & Walls (2008) examined variations of lifetime healthcare costs in Canada amongst gender (i.e., men and women). Women incurred a mean cost of US$89,741 over a lifetime in hospital and physician costs, 40% more than the US$64,091 incurred by men. Women also showed higher per capita costs than did men during peak childbearing years. Total costs across the lifespan may also be higher for women as the typical female life expectancy is almost six years longer than the typical male. However, on an annual basis, beyond the age of 75, both males and females are about equally likely to incur high, moderate or low costs (Forget et al., 2008). Thus gender differences are not likely to be present in the data collected for the current study.

In summary, the research reviewed above indicates that costs of care of all elderly people are significant, and are influenced by a number of factors in addition to their cognitive and residential status, such as functional status, age, gender and proximity to death.

Singapore (the current study). Study 1 therefore seeks to gather such data on the costs of care for older people in Singapore, and to evaluate the influences of age (but will not consider proximity to death in this cross-sectional study), MMSE-measured cognitive status and a self-reported functional status, gender and residential status. Data about caregiver/informant characteristics will be presented, along with data regarding time spent in caregiving activities, and healthcare utilization. The hypothesis is that the cost of care will increase with age, cognitive decline and functional decline, and be higher for female before age of 75 years.

In Study 2, costs of care for this sample of PWOD will be compared to the sample from Chapter 3, on PWD. It is hypothesized that the costs for this sample without dementia will be lower than the costs identified for the sample with dementia in Chapter 3.

Study 1: Caregivers characteristics and informal cost of care of PWOD

Method

Participants

A total of 3,000 patients were screened in 3 polyclinics with approximately 1000 patients per polyclinic over the 12-months period from November 2013 to October 2014. The inclusion criteria were all participants were 60 years and above. They had to be accompanied by a reliable caregiver or other informant and be able to provide informed consent. They had adequate language skills and be fluent in English, Mandarin or Malay. The exclusion criteria included having major and active psychiatric illness; and significant physical, visual, and hearing impairment.

Patients-informant dyads were approached by researchers during their polyclinic visits. The study was explained to them. If they were willing to participate, informed consent was obtained, but if not, reason(s) for refusal was obtained instead. No subject was included in the study unless informed consent was first provided.

Eligible patient-informant dyads that provided informed consents completed the informant Ageing and Dementia item 8 (AD8) at the waiting area of the polyclinic. Trained research psychologists or raters assisted in the administration of the AD8 to informants of eligible participants at the waiting area of the polyclinic. In the event that the patient attended the polyclinic alone, the informant consent and AD8 were conducted over the phone.

Resource utilization in dementia (RUD) questionnaire was also administered to the informants of participants.

All AD8 screening results were provided to their attending doctors for consideration of further referral. Of these 3,000 patient-informant dyads screened during phase 1. One thousand six hundred and fifty (1,650) with informed consent and informant AD8 done were enrolled. Of those enrolled, 300 patient-informant dyads meeting inclusion criteria were recruited for phase 2 of the study being carried out at Memory, Aging and Cognition Centre (MACC) at the National University of Singapore (NUS). Of these 300 patients-informant dyads, 137 agreed to participate in this add-on study on the cost of elderly without dementia. Resource utilization in dementia (RUD) questionnaire was also administered to the caregivers of patients (See Figure 16).

Measures

Cognition screening AD8. In this study, the eight-item interview to differentiate Ageing and Dementia (AD8) is used to detect cognitive impairment (Galvin, 2005). The possible score ranges from 0 to 2 with a score range of “0-1” being considered normal and a score of 2 or greater suggested cognitive impairment. These 137 patients were given the AD8 test and all had scores of 2 or more, suggesting cognitive impairment but no dementia.

Cognition screening MMSE. Data on dementia people general cognitive abilities was collected using the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). The MMSE score measures the severity of the cognitive impairment on these PWOD. The possible MMSE score ranges from 0 to 30, with lower scores indicating more severe impairment (0-10: severe, 11-20: moderate and 21-24: mild). Any score greater than or equal to 27 points (out of 30) indicates a normal cognition.

Subjective level of Function. Participants were asked questions on their ability to live independently, Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). The score ranges from 1 to 4. The scores of 1 and 4 indicate complete independent and dependence respectively for the participants, while 2 represents some assistance is required for basic ADL and 3 represents assistance with IADL.

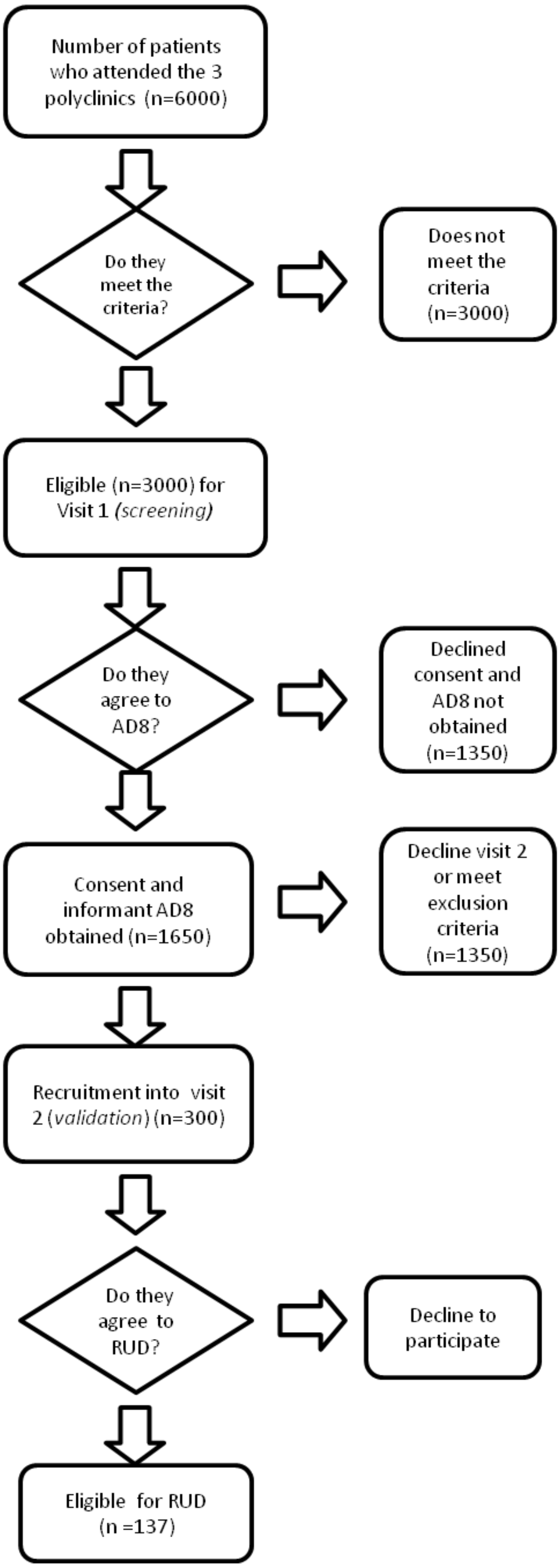

Figure 16. Sampling methodology for interview participants in Study 1

Procedures

Ethics approvals were obtained from the National Healthcare Group Domain-Specific Review Board, National University Hospital Services and the James Cook University Ethics Committee before any data was collected. Informed consent for the study was taken from the patient and caregiver and then the caregivers were interviewed individually to complete the AD8.

Analysis

Valuation of Informal cost. Informal costs are the sum of the opportunity cost of the time forgone by caregivers and hours of paid employment foregone by retired and semi-retired caregivers who would otherwise be still in the workforce.

As in Chapter Three, valuation of caregivers' time is calculated for two subgroups of caregiver: employed people and retirees. For employees, indirect costs are calculated in terms of productivity losses, i.e. missed days or part-days of paid work due to caregiving responsibilities. Cost-estimates are based on the median gross monthly income of full-time employed worker in Singapore in 2014, which was SG$3,770 (Department of Statistics, 2014). Time taken from paid employment was valued by using the 2014 census median income data from the Singapore Department of Statistics, where SG$21.42 represented the median wage earnings of the Singapore population, with an assumption of a 44 - hour work week.

For retired caregivers, the time spent on caregiving (i.e., informal care) as indicated on the RUD was evaluated as follows: Daily hours of assistance with ADLs and IADLs was maximized at 8 hrs per day each and multiplied by SG$ 6.25 per hour as the base rate (based on the minimum salary of SG$1,000 in Singapore).

The cost of employing a live-in paid FDW (as examined in Chapter Three) is not relevant here as the patients in this study did not have dementia. As these patients were not cognitively impaired and did not have dementia, they were capable of performing ADLS, IADLS with minimum supervision. The FDWs were employed by PWOD mainly to assist in the household chores for the family. Hence, no time is specifically forgone by these FDWs in taking care of the PWOD.

Results

Caregiver demographic characteristics

The mean age of the caregiver for PWOD is 61.65 (*SD* = 12.45). More than half of the caregivers were female (62.04%) with majority being their spouses (67.15%) and children (28.47%). The rest were others (2.92%) and siblings (1.45%). More than half of the primary caregivers were not employed (66.42%). More than three quarters of the caregivers (83.21%) stayed with the patients and the rest did not (16.79%). Slightly more than half (51.09%) of these primary caregivers did not have any other caregivers, with the rest having 1 other caregiver (25.55%), 2 other caregivers (15.33%), 3 other caregivers (5.11%) and 4 other caregivers (2.92%). Twenty of these families (14.60%) had FDWs. These FDWs were mainly to assist in the household chores (See Table 20).

Caregiver ADL, IADL and Supervision

The mean number of hours that caregivers spent in assisting ADLs was 0.45 hours per day (*SD* = 1.80) and in assisting IADLs was 3.28 hours (*SD* = 3.19) per day. An additional mean of 1.03 hours per day (*SD* = 2.99) was spent on supervision of the patient.

Table 20

Baseline demographic details of caregivers

	N = 137
Age (years) (SD)	61.65 (12.45)
Gender (% female)	62.04
Relationship to patient (%)	
Spouse	67.15
Sibling	1.45
Child	28.47
Other	2.92
Currently working for pay (%)	
Yes	33.58
No	66.42
Living with patient (%)	
Yes	83.21
No	16.79
No of other caregivers (%)	
0	51.09
1	25.55
2	15.33
3	5.11
4	2.92
Level of contribution of caregiving by primary caregiver compared with other caregivers involved	
1-20%	13.86
21-40%	28.47
41-60%	27.74
61-80%	12.41
81-100%	17.52
Presence of foreign domestic worker (%)	14.60

Caregiver Healthcare Utilisation

Only 3 caregivers (2.19%) were admitted to the hospital during the last month, with an average stay of one and a half nights' stay at general wards. Slightly more than half (52.5%) of these caregivers had visited a health care professional during the last month with an average 1.2 visits during this one - month period. Almost a quarter

(70.83%) of the caregivers was taking medications. Many of these caregivers were taking medications for more than one other chronic health problems. The most common medications reported by these caregivers were for hypertension (52.94%), hyperlipidemia (43.53%), diabetes (20.00%) and osteoporosis (12.94%).

Patient Living Accommodation

Almost all PWODs (97.10%) were living in their own homes. There were 3 patients living in intermediate forms of accommodation (not dementia-specified) and one patient living in long term residential care facility (for non-dementia illness).

Patient Healthcare Utilisation

Slightly more than half (55.83%) of these PWODs had visited a health care professional during the last month with an average 1.2 visits during this one - month period. These PWODs had more than one other chronic health problems. The most common other chronic health problems reported were hypertension (35.82%), diabetes (25.37%) and hyperlipidemia (23.88%).

Informal Cost of Care

The median monthly cost of informal care for PWOD was SG$456.42. The median annual cost of informal care was SG$5,477.03.

Study 2: Comparison of Caregiver characteristics for PWD and PWOD

Method

Participants

Participants were those from study 1, PWOD, as described above and those from Chapter Three, PWD. Patients with Mild Cognitive Impairment (MCI) were classified by MCI subtypes (amnestic MCI, non-amnestic single domain MCI, multiple domain MCI with an amnestic component, and non-amnestic multiple domain MCI) according to the revised MCI criteria (Petersen et al., 2002).

Measures and Procedure

All data was collected using the measures and procedures previously described.

Results

Age and Gender

The mean age of the caregiver for PWOD was older at 61.65 (*SD* = 12.45) compared to those PWD at 53.24 years (*SD* = 14.22). Females were the majority caregivers for the PWD and PWOD (See Table 21).

Relationship to patients

Spouses were the main caregiver for PWODs while children were the main caregivers for those PWDs. A few FDWs (1.96%) were the primary caregivers for PWD but there was none for those PWOD.

Employment Status

A third (33.58%) of the caregivers for PWOD was gainfully employed while about half of the caregivers for PWDs were gainfully employed.

Living Accommodation

The majority of these PWODs (83.21%) stayed at home with their families and lived in their own homes (96.67%). But only slightly more than half of PWD (54.90%) stayed with their families and less than half of them (47.06%) actually lived in their own homes.

Other caregivers

More than half of the caregivers (51.09%) were sole caregivers in taking care of PWODs while almost half (49.10%) of the primary caregivers had one other caregiver in helping them to take for PWDs.

Level of contribution by primary caregiver

Less than a third (28.47%) the primary caregiver spent 21- 40% of their time in taking care of PWODs, while a third (33.33%) of the primary caregivers spent 1-20% of their time in caring for PWDs.

Presence of FDWs

A few primary caregivers employed FDWs (14.60%) in their households for PWOD. These FDWs were mainly to do housekeeping chores for these families. However, more than half of the households (58.82%) had employed FDWs for PWDs.

ADL, IADL and Supervision

The time spent by caregivers on ADL, IADL and supervision for PWODs were much lesser compared to those PWDs (See Table 18). This was mainly because these PWODs had fewer problems in their daily activities and hence also required less supervision compared to those with dementia.

Informal cost of care

The mean annual informal cost of care for PWOD was SG$ 5,477.03 while those PWD was SG$ 44,530.55.

Table 21

Baseline demographic details of caregivers for people with and without dementia

	Patients without dementia (*n* = 137)	Patients with dementia (*n* = 51)
Age (years) (SD)	61.65 (12.45)	53.24 (14.22)
Gender (% female)	62.04	70.59
Relationship to patient (%)		
Spouse	67.15	27.45
Sibling	1.45	1.96
Child	28.47	41.18
Other	2.92	9.80
Foreign Domestic Worker	0.00	1.96
Residential Care Facility (%)	0.00	17.65
Currently working for pay (%)		
Yes	33.58	47.06
No	66.42	35.29
Residential Care Facility (%)	0.00	17.65
Living with patient (%)		
Yes	83.21	54.90
No	16.79	45.10
No of other caregivers (%)		
0	51.09	9.80
1	25.55	49.10
2	15.33	15.69
3	5.11	3.92
4	2.92	3.92
Residential Care Facility (%)	0.00	17.64
Level of contribution of caregiving by primary caregiver Compared with other caregivers involved		
1-20%	13.86	33.33
21-40%	28.47	21.57
41-60%	27.74	9.80
61-80%	12.41	1.96
81-100%	17.52	15.69
Residential Care Facility (%)	0.00	17.64
Presence of foreign domestic worker (%)	14.60	58.82
ADLS (hours) (SD)	0.45 (1.80)	2.48 (3.32)

IADL (hours) (SD)	3.28 (3.19)	3.31 (2.90)
Supervision (hours) (SD)	0.03 (2.99)	2.36 (3.75)
Mean Annual informal cost of care (SG$)	5477.03	44530.55

Factors related to informal cost of care

A multiple regression model with cost of care as the dependent variable and MMSE, age and independence level as independent variables was conducted. The regression showed a negative coefficient of 38.35 with MMSE, negative coefficient of 7.71 with age and positive coefficient of 44.14 for the independence level (see Table 22). The mean annual informal cost of care is negatively correlated with MMSE and age but positively correlated with the level of dependence of PWOD.

Table 22

Multiple Regression Model on Informal Cost of Care

					95% Cl	
Variable	*B*	*SE*	*t*(39)	*p*	*LL*	*UL*
MMSE	-38.35*	17.14	-2.24	.03	-72.26	-4.43
Age	-7.71	9.36	-.83	.41	-26.24	10.81
Dependence level	44.14	144.91	.30	.76	-242.56	330.84

Note. Cl = confidence interval; *LL* = lower limit; *UL* = upper limit.

Discussion

Level of contribution by primary caregiver

About a third of the primary caregivers of PWDs spend only up to a fifth of their time in caregiving, whereas the majority of the caregiver/informants for PWODs spent between 20% and 60% of their time in caregiving. This apparently contradictory result may be explained by the role of FDWs, who had a much greater role in looking after PWDs than in assisting PWODs. More than half of the families of PWDs had FDWs assisting them, compared with a minority of FWDs assisting families of PWODs.

Importance of support by family caregivers

More than three quarters of the caregivers (83.21%) stayed with PWODs. In Singapore, close to 95% of older people co-reside with family members, highlighting the importance of community support by family caregivers (Mehta, 2005).

Factors related to informal cost of care

Study 1 hypothesized that the informal cost of care would increase with age, cognitive decline and functional decline, and be higher for female before age of 75 years. The data showed that the mean annual informal costs of care of PWOD is SG$5,477.03.

The negative correlation between the informal cost of care and age is due to the profile of PWODs in a community dwelling environment. These PWODs were at the polyclinic with more than a quarter of them (26.31%) incurring no informal cost of care as they are totally independent with zero scores on measures of ADL, IALD and supervision time by their caregivers. These PWODs are mainly at the polyclinic for their annual check-up or follow-up with their doctors, and the caregiver/informants do not spend significant time caring for these generally healthy PWODs, hence incurring minimum cost. The study findings also showed that PWODs tend to have higher costs if their dependence level on the caregiver is high.

This study showed that the mean cost of care across the lifespan is higher for a typical female than a typical male. The mean cost of care for a female during the lifespan below the age of 75 is SG$511.84 while that for a male is SG$415.76. This is quite likely due to the child bearing period for the female (Forget at el., 2008). Similarly, the cost of care for a female above the age of 75 years is also higher at SG$444.99 than a typical male at SG$279.96 as a female life expectancy is almost six years longer than the typical male thus older females may be increasing this average cost (Forget at el., 2008). Women are also generally more health conscious help seeking for health concerns throughout the lifespan than men (Smith, Mayer, & Wittert, 2006). Smith, et al. (2006) also noted that the health of men is poorer than that of women, mortality rates are higher and men use health services less often than women.

Comparison of informal cost of care for PWD and PWOD

Study 2 compared this data to that of Chapter 3 for PWD. It was hypothesised that the costs for this sample of PWODs will be lower than the costs identified for the sample of PWDs in Chapter Three. It was found that the mean annual informal cost of care for PWODs was SG$ 5,477.03 while those PWDs was SG$ 44,530.55. This difference was not unexpected as patients with dementia generally required more time in taking care of them due to their cognitive impairment and functional disability compared to those patients without dementia. The difference between the two samples is striking. Despite recruitment from different sources for the two samples, this data provides clear evidence of the high costs of informal care for PWDs as compared to PWODs.

Chapter Five

Screening: Is cost a barrier to screening for dementia?

Introduction

As covered in Chapter Two of this thesis, the cost of dementia care is enormous globally and in the Asia Pacific region. In this chapter, a literature review of the types of screening and whether screening is a barrier to screening for the elderly people will be covered. In the early stages of illness, symptoms may be sub-clinical, or not noticeable to the patient or their caregivers. Screening programs, where trialed, aim to identify dementia related illnesses at this early stage. Lin, O'Connor, Rossum, Perdue and Eckstrom (2013) noted this cognitive testing or early diagnosis test based on systematic reviews for cognitive impairment in community-dwelling older adults (with MCI or mild to moderate dementia) in primary care setting has not been shown to improve outcomes for elderly over 65 years. However, Hendry, Quinn, Evans and Stott (2015) noted that informant single screening question (SSQ) tool is shown to be more accurate in detection of dementia in older people above 65 years in acute hospital care, than in screening for delirium.

Diagnosis of Dementia

There are many different types and causes of dementia as covered in Chapter One of this thesis. Even though the symptoms of the different types of dementia are very similar, however, it is usually difficult to diagnose the type of dementia by symptoms alone. Under normal situations, the symptoms must be present for more than six months to proceed for a further diagnosis (MD Guidelines, 2016). The diagnosis of dementia is generally performed by cognitive testing, imaging and laboratory test.

Brain imaging methods can be used to diagnose dementia (Lin et al., 2013). However, in some cases, samples of the brain tissues have to be removed to ascertain the abnormalities. Lin and colleagues (2013) noted that a brain biopsy during life, or autopsy following death of the patient, can be performed. Further complicated diagnosis involving the tissues in the brain like cortical and sub-cortical structures may require referral to a specialist. Brain biopsy is extremely rare, thus for most cases of dementia, definitive diagnosis is only possible through autopsy.

Laboratory tests. Laboratory tests are usually performed to differentiate the reversible causes from the un-reversible causes of dementia. A complete blood cell count (to exclude anemia and infection), urinalysis (to exclude infection), serum electrolyte, glucose and calcium levels, blood urea nitrogen, serum creatinine level and liver function tests (to investigate metabolic disease) may be performed on the patient to ascertain the diagnosis of dementia (Report of the Quality Standards Subcommittee of the American Academy of Neurology, 1994). These tests include deficiency in certain vitamins (vitamin B_{12}, vitamin c), hormones (thyroid-stimulating hormone (TSH) and enzymes (liver). Deficiency in these may result in disorientation in the elderly (Aldasouqi, 2011) which may mimic symptoms of dementia.

The symptoms associated with these problems are reversible with appropriate treatment. However, Buson and Solomon (2011) noted that the problem is complicated when patients who have early dementia also suffer these same symptoms. The symptoms of dementia are not reversible and will only degenerate further, without proper treatment.

Imaging. A Computer Tomography (CT) scan or Magnetic Resonance Imaging (MRI) scan may be performed on a patient to confirm the diagnosis and clarify the type of dementia (Bonte, Harris, Hynan, Bigio, & White, 2006). For example, an image of the brain may reveal vascular damage resulting from heart attack or stroke, or from small vessel disease in the brain, leading to a diagnosis of vascular dementia (Bonte et al., 2006). In addition, a CT scan or MRI scan is useful to detect treatable brain conditions such as hydrocephalus, where there is excessive fluid in the brain.

Ishii (2002) noted that PET (Positron Emission Tomography) can help differentiate among types of dementia, including frontotemporal dementia. In another study by Engler, and colleagues (2006) showed PET with Pittsburgh Compound B protocol to accurately measure the amount of amyloid in the brain and predict Alzheimer disease.

Dougall, Bruggink and Ebmeier (2004) also posited that imaging tests like PET Scans (Positron Emission Tomography) and SPECT Scans (Single Photon Emission Computed Tomography) can be used to assess brain pathology. Both have the ability to provide more specific information about brain structure and function. SPECT imaging is able to differentiate vascular dementia and front-temporal dementia from Alzheimer’s disease (Dougall, Bruggink & Ebmeier, 2004).

Zhang and colleagues (2014) has further reported on the PET imaging test using carbon-11 Pittsburgh Compound B is a radiotracer (PIB-PET) in identification of varied types of dementia, specifically Alzheimer's disease. The radiotracer PIB-PET is found to be highly accurate with 86% accuracy in predicting patients with mild CI who would develop Alzheimer's disease within two years. Ha (2009) also found similar results and discovered in PET imaging test involving either PIB or carbon-11 dihydrotetrabenazine (DTBZ) in the United States, with more than one quarter of patients tested positive for mild cognitive impairment.

Screening for Dementia

What is a screening programme? Screening is a means to identify an unrecognized disease in individuals without signs or symptoms. It is normally conducted in a population- based setting. Screening is done on people with pre-symptomatic or unrecognized symptomatic disease. Hence, screening tests are distinctive in that they are using performed on individuals in good health standing.

Objective of screening. The goals of any screening test are mainly two-fold: to separate individuals with a high probability of getting the disease from those with a low probability, and to identify unrecognized disease. Patients will be placed under treatment if the disease is communicable and steps such as quarantine may be taken to prevent them from being a danger to the community.

In order for screening outcomes to be effective, it is useful for such tests to be brief and accurate. Once the screening test is positive, the patient can then proceed for a diagnostic interview and a clinical examination. These tests can be conducted by the doctor or a specialist. The knowledge of early dementia and effective treatment resulting in positive health outcomes can be carried out by randomized controlled trial (Fuchs, Clare, & Woods, 2013)

Types of screening. Screening interventions are designed to detect disease early in a primary community healthcare setting (Burke, Tarini, Press, & Evans, 2011). This is to enable earlier interventions and management so as to reduce the mortality rate by those who are affected by a disease. Though screening could result in an early diagnosis, not all screening tests benefit the person being screened (Burke, et al. 2011). Adverse effects of screening such as over-diagnosis, mis-diagnosis, and under-diagnosis may result a false sense of security in the patients. For these reasons, the screening tools should have a good sensitivity and acceptable specificity. These requirements are especially applicable to for diseases with low incidence.

However, screening intervention is not designed to be diagnostic. Many types of screening exist with different objectives. Types of screening include mass screening means that, the screening of a full population or a subgroup. It is offered to all or any, regardless of status or health standing of the individual. High risk or selective screening is solely conducted among risk populations. Multiphasic screening applies to at least two screening tests to a large population at one - time period rather than having separate screening tests for single diseases.

Types of screening programmes

Population based screening programmes. In several countries there are population-based screening programmes operated at the national level like the United Kingdom and Singapore. These include cancer screening test, antenatal and newborn screening, pap smear test or cervical cancer screening, mammography test to discover breast cancer, colonoscopy test to discover colorectal cancer, dermatological check to discover melanoma, faecal occult biopsy screening test for bowel cancer, PPD test to screen for exposure to tuberculosis, breast screening, ultrasound scan test for abdominal aortic aneurysm, screening test of potential sperm bank donors, screening of for Metabolic Syndrome, diabetic eye screening, Beck Depression Inventory test to screen for depression. Opportunistic screening is such screening being conducted for a targeted group when an opportunity arises. The case of dementia screening occurring when an elderly patient visits a primary care practitioner for other ailments is an example of opportunistic screening.

School-based screening. Most public schools in the United States and Singapore screen students for hearing and vision deficiencies and dental issues. As well as screening for spinal and posture problems like spinal curvature is typically applied. However, some test such as scoliosis (unlike vision or dental issues) is found in a small population and since students should take away their shirts for screening, many countries have not mandated scoliosis screenings, or permit them to be waived with parental notification.

Screening programs in Singapore. In Singapore, there is subsidized screenings for mammography for women who are above 45 years old and colonoscopy for men and women and faecal occult blood test for the elderly above 55 years old. For children, there is free dental screening for basic dental treatments and vision and hearing impairment for all public school going students from 7-19 years old. For mothers who have just given birth to babies, they receive free antenatal and newborn screening.

Limitations of screening

Screening may detect medical conditions at an early stage before the symptoms. However, screening these tests is not solid proof. Test results may be incorrect. Healthy people who are actually healthy may be shown to be sick (false positive), or sick people who actually have the disease are tested to be healthy (false negative). Some limitations of screening are the cost on the use of medical resources and public services on a majority of patients who are misdiagnosis. Misdiagnosis will deprive resources away from those who actually need them. Adverse effects of screening procedure may include stress, anxiety, discomfort, emotional instability and depression from radiation and chemical exposure. Not all screening is carried out in a primary care setting due to reasons such as insufficient time allotted to the patient visit, inadequate reimbursement for cognitive work, and uncertainty concerning the value of early diagnosing. Another concern is the current lack of brief sensitive and predictive measures that differentiate between healthy older adults from those diagnosed with mild dementia.

Screening Tests for Dementia

Studies have shown that more than 50% of individuals in the United States with mild or moderate dementia have not been diagnosed by doctor and clinicians using patient's records and physical examination (Boustani et al., 2003; Kotagal, 2014). Hence, screening tests may be helpful to identify individuals with undiagnosed early dementia and allow patients and caregivers to receive treatment in the early stages of the disease.

There are many screening instruments available. The details of commonly used and researched methods are below.

Most screening tests for dementia are divided into four areas: 1) Cognitive tests of patients, 2) Functional assessments on the patients and their informants; 3) Informant based screening tests and 4) Genetic mutations testing.

Cognitive tests. Cognitive tests are easy and fast, typically taking about 5 to 15 minutes. Hence, these tests are popular with clinicians. Cognitive tests may be administered directly with the patient. These tests include the MMSE (Folstein, Folstein & McHugh, 1975), the Abbreviated Mental Test Score (AMT; Hodkinson, 2012), the Modified Mini-Mental State Examination (3M; Teng & Chui, 1987), the Cognitive Abilities Screening Instrument (CASI; Teng et al., 1994), the Trail-making test (Tombaugh, 2004), the Alzheimer's Disease (AD8; Galvin, 2005) and the Clock Drawing Tests (CDT; Royall, Cordes, & Polk, 1998).

Functional assessment tests. These are informant-based practical tests. Such tests are conducted on the informants including The Bristol Activities of Daily Living Scale (BADLS; Bucks, Ashworth, Wilcock & Siegfried, 1996), The Barthel index (Mahoney and Barthel, 1965), The Functional Independence Measure (Keith et al.,1987) and the Instrumental Activities of Daily Living (IADL) questionnaires (Lawton & Brody, 1969). These instruments are easy to use because they cover wider scope on patient type, time period and cultures (Sheehan, 2012). The main limitation of functional assessment tests is the absence of caregivers. Sheehan (2012) noted that the end result is some cognition functions are not tested.

Informant-based screening tests. These require an informant (such as a spouse or sibling) to fill out a questionnaire. The questionnaire asks about the person's daily activities and cognitive functioning. These informant-based screening tests include the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE; Jorm, 2004) and the General Practitioner Assessment of Cognition (GP-Cog; Brodaty, 2002). Following a positive screening result, clinicians will provide diagnostic consultation to these patients. Clinical history and tests of memory, cognitive function, attention and language ability, emotional and psychological changes are further used to diagnose other possible related causes of dementia.

Genetic mutation tests. Testing for genetic mutations is a new screening test. This test could lead to early detection of individuals with potential Alzheimer's disease. Many patients with dementia are worried that their genes may be passed on to their children. Family members with dementia are also worried that they may inherit the genes themselves.

There are two categories of genes that influence whether a person develops Alzheimer’s disease. They are risk genes and deterministic genes and people with

Alzheimer disease are found to have both genes in them (Alzheimer’s Association, USA, 2016). There are basically two types of dementia related to genes, namely early onset AD (which occur before 65 years) and after onset AD (which occur after 65 years). Three genes have been identified to cause inheritance dementia. According to Alzheimer’s Association, USA, 2016, they are amyloid precursor protein gene (APP) and two presenilin genes (PSEN-1 and PSEN-2). People with one of these genes may develop dementia in their 30s and 40s (early onset dementia).

Instruments for dementia testing

While there are many possible methods of screening as noted here, there are several cognitive and functional tests that are commonly used with older individuals or their caregivers or informants. There are many measurement instruments for screening dementia. These are now described below.

Ascertain Dementia 8-item (AD8; Galvin, 2005). This questionnaire has a simple scoring system. It has eight questions about cognitive functions including the patient’s memory, orientation to time and place, daily functioning, and interest in activities. It is an informant based assessment because the patient's informant, usually a spouse, their siblings or caregiver is asked to assess the patient. It takes less than three minutes to complete. Answers are in a yes or no format, giving a score from 0 to 8. The higher the score, the more likelihood is the patient having dementia. Usually, a score of 2 or more “yes” indicates that the patient may have dementia and further diagnostics test have to be done. One key advantage of the AD8 test is that it can be conducted face-to-face or via telephone interview. There is no need to have a physical location. It can be used for informants of different education levels and age. The main key disadvantage is that some caregivers may refuse to participate or not be present.

The Mini–Mental State Examination (MMSE; Holstein, Holstein & McHugh, 1975). This is a 30-point questionnaire to screen and test for cognitive impairment. It is also used to determine the severity of cognitive impairment of a patient and tracks the course of cognitive changes over time. This feature often makes it to be an effective tool to record an individual's response to treatment. Result showed that the Holstein Mini-Mental State Examination (MMSE) has a sensitivity of 71% to 92% and specificity of 56% to 96% in primary care populations (Boustani et al., 2003).

It is a brief test and takes about 10 minutes to complete it. Cognitive functions including arithmetic, memory and orientation are being tested. Any score greater than or equal to 25 points indicates a no cognitive impairment. A score of less than 9 points indicates severe dementia, 10-18 points indicates moderate dementia and 19-24 points indicates mild cognitive impairment. Unlike the AD8 scoring system, the MMSE scoring system is such that the lower the score, the more likelihood of the patient having severe dementia. One key disadvantage is that these raw score may need to be corrected for educational attainment and age, while the AD8 does not require (Boustani et al., 2003). The MMSE is less specific in people with less formal schooling populations in third world country and is also less sensitive among highly educated populations. In addition, the MMSE is insensitive to mild cognitive impairment. It does not differentiate dementia from delirium (Boustani et al., 2003). Lastly MMSE requires the patient to read and write. This hinders patients who are illiterate to participate in the MMSE questionnaire.

One key advantage is that the MMSE is useful in differentiating the types of dementias. Patients with Alzheimer's disease usually score lowly on orientation and recalling things or events as compared to patients suffering from dementia with Lewy bodies, Parkinson's disease dementia and vascular dementia (Boustani et al., 2003).

The Montreal Cognitive Assessment (MoCA; Nasreddine and colleagues, 2005). The MoCA test is a one-page 30-point test administered in approximately 10 minutes. The MoCA test validation study (Nasreddine et al., 2005) has shown that it is an effective tool for detecting Mild Cognitive Impairment (MCI) and early Alzheimer's disease as compared with the popular Mini-Mental State Examination (MMSE) test. According to the validation study (Nasreddine et al., 2005), the sensitivity and specificity of the MoCA for detecting MCI were 90% and 87% respectively, as compared with 18% and 100% respectively for the MMSE. In the same study, the sensitivity and specificity of the MoCA for detecting early AD were 100% and 87% respectively, as compared with 78% and 100% respectively for the MMSE (Nasreddine et al., 2005).

The Test Your Memory (TYM**;** Yazar, Bergström and Simons, 2012). This is a new cognitive test comprising of ten tasks covered on both sides of a single sheet of soft card. It takes about five minutes to finish the test. It has to be completed by the patient and may be completed under the supervision of a health professional. The complete score is 50 marks. The average TYM score is 47 and above. The lower the score, the higher likelihood is the patient having AD.

Some of the advantages of the TYM are that it is fast, as the patient fills in the form themselves, hence saving time. It also acts as a patient’s permanent diary. As the records are filled by the patient, the TYM may be a permanent self-written record of a patient’s accomplishment with dates. This is useful for referrals back to for future usage. It also tests different cognitive domains. The TYM tests cover ten different cognitive domains as well as the inability to recall the past experiences, changes in information and skills in recalling what they see in different environment which are present in early Alzheimer's disease. The TYM has a very clear distinction between the scores of normal controls (average 47) and patients with mild AD (average 33). A cut off of 42 out of 50 includes a high sensitivity of .93 and specificity of .86 in the diagnosis of AD (Brown, George, Dawson, Brown, & Clatworthy, 2009). It is also a powerful tool in detecting mild Alzheimer's disease, successfully detecting dementia in 93% of patients, compared with 52% for the mini-mental state examination (Brown et al., 2009).

The Abbreviated Mental Test Score (AMTS; Hodkinson, 2012*)***.** It was introduced to detect the likelihood of dementia in the elderly by Hodkinson (2012). The AMTS is used more widely in medication purposes such as to assess for confusion and different cognitive impairment. The patient answers the 10 questions. Each correct answer has a score of one point. A score of 7-8 or less suggests cognitive impairment at the time of testing, though more formal tests are necessary to verify a diagnosing of dementia, delirium or different causes of cognitive impairment (Hodkinson, 2012). The lower the score, the more likelihood is the patient having dementia.

Other measurements of detecting prevalence of CI and dementia

Computer Modelling (Vickland, McDonnell, Werner, Draper, Low & Brodaty, 2010). Other than screening to detect dementia prevalence, computer modelling has been used to test hypothetical scenarios regarding dementia prevalence in Australia (Vickland et al., 2010). The study team developed a computer prevalence model using data in Australia from 2001 and extrapolated to 2040. Using virtual experiments, Vickland et al. (2010) set out to achieve three objectives, mainly, to delay the onset of dementia, to delay the progression of the severity of dementia and to eradicate certain types of dementia. Vickland et al. (2010) noted that by postponing or delaying the onset of dementia by preventive or therapeutic means could reduce the prevalence of dementia as elderly may suffer and die from other non-dementia disease before they develop dementia. Vickland et al. (2010) concluded that delaying the onset of dementia will reduce future prevalence of 16% for a 2-year delay and 37% for a 5-year delay for population based testing. Other studies (Brookmeyer, Gray, & Kawas, 1998; Jorm, Dear, & Burgess, 2005) showed different results. These reductions of future dementia prevalence by Vickland et al., (2010) were smaller compared with the reductions predicted by Brookmeyer, Gray and Kawas (1998) and Jorm and colleagues (2005). The Brookmeyer model predicted 23% and 47% reductions for the United States and the Jorm and colleagues (2005) model predicted reductions of 21% and 44% for Australia. On the third objective, Vickland et al. (2010) concurred that dementia is unlikely to be completely eradicated in elderly as postmortems of very old people had been identified to not having pure dementia but mixed dementias (Schneider, Arvanitakis, Bang, & Bennett, 2007)

Total Risk Score (TRS; Shaik et al., 2015). Another measure to detect CI and dementia include using a composite score of selective risk factors and compile them into a total risk score (TRS). TRS is used to identify vascular and socio-demographic risk factors for case finding of CI in primary health care (Shaik et al., 2015). Shaik and colleagues (2015) posited that elderly who are 70 years and above, having diabetes, history of stroke, and female gender, and subjective cognitive complaints have higher risk of CI. These risk factors (such as age, gender, education, certain medical conditions and subjective cognitive complaints) are combined into a composite score, TRS in detecting CI. Using TRS, Shaik and colleagues (2015) noted that the combined utility of additional dementia screening tests such as the AD8, MMSE, or MoCA improve the prediction of CI and dementia in global cognitive composite scores determined by a formal neuropsychological evaluation.

Potential Harms and Benefits of screening

Boustani, Watson, Fultz, Perkins and Druckenbrod (2003) noted that the best evidence for or against screening for dementia would be derived from a well-designed randomized control trial of screening with health outcomes. No such trial has been completed. In the absence of such a trial, evidence for or against screening comes from studies of the prevalence of undiagnosed dementia, the accuracy of screening instruments, the efficacy of treatments for people with dementia detected by screening, and the harms of screening and treatment (Boustani et al., 2003).

The harms and benefits of dementia screening have not been systematically studied (Boustani et al., 2003). In order for screening to be supported by the government, there must be sufficient evidence to show that potential benefits outweigh potential harms.

Potential harm includes issues relating to reliability, results of screening, resources and costs. Some considerations of these concerns are as follows:

Screening is not 100% reliable. Many researchers are concerned on the possibility of high rates of “false positives” in the screening compared to “true positives” in the outcome, hence causing unnecessary stress to patients and care givers. Testing for generic risk has the same problem as other biological or imaging measurement- an insufficiently close relationship to outcome (Clinical guideline NG31, UK, 2015).

Perceived public concerns. Perceived public concerns on screening include its potential effects on individuals’ ability to maintain a driver’s license, live independently and obtain residential and health insurance policies or acceptance into a continuous care retirement community (Brayne, Fox, & Boustani, 2007; Drickamer & Lachs, 1992).

Limited availability of research. Little research is available on questions such as effect of false-positive screening results for dementia on individuals and families (Brayne, Fox, & Boustani, 2007). One US dementia screening and diagnosis program showed that patients had high refusal rates for dementia diagnostic workup following positive screening results. Refusals were also associated with ethnicity, age, and perception on dementia symptoms (Brayne et al., 2007).

Informal versus formal Costs. Individual cost and the health care system cost have to be considered differently taking into account the need to balance the expense of screening with medical care expenditure and also the relative costs allocated to primary, secondary and tertiary prevention of the disorder as well as to the other common conditions that cause morbidity but are under-resourced (Angelis, Tordrup, & Kanavos, 2015).

Substantial Resource Utilization. Implementation of such screening would require substantial resources, system redesign, and overcoming significant barriers such as patient’s acceptance of diagnostic workup, availability of dementia care coordinators, and the presence of interdisciplinary dementia care specialists (Brayne et al., 2007).

Development of treatment plan. The additional burden of screening, communicating the results and developing a treatment plan with the patient and care giver need to be considered as it involves both time and money for the patient and caregiver (Brayne et al., 2007).

Discovery of co-existing health related illness. In the process of screening for dementia, the treatment for this disease may lead to discovery other additional co-existing health related problem due to the treatment process (Alzheimer's Association, USA, 2016).

Risk of depression and anxiety. Because at least 50% of patients with a positive result on a screening test will not meet criteria for dementia, any screening program must be linked to a source of diagnostic interviews. Although these interviews could be done by primary care physicians, relatively few non-specialist physicians engage in such interviews as standard practice. After a positive screening result, patients and families may have to wait to obtain a referral for a diagnostic work-up, potentially increasing anxiety and worry (Boustani et al., 20003; Jha, Tabet, & Orrell, 2001).

Time and Cost of screening. The time incurred of taking tests and waiting for results may result in depression and anxiety for the patients and their caregivers (Boustani et al., 2003). There are also cost incurred for the screening tests for patients and caregivers.

Possible labeling effects. If patients are screened and tests are positive to be having dementia, labeling such persons with a disease could potentially cause unnecessary anxiety (Boustani et al., 2003).

Potential benefit includes:

Early Treatment of the condition. Individuals identified with early dementia by screening may have the opportunity to discuss the nature of the syndrome, its prognosis, and future planning with regard to health care, safety, and finances and early treatment of the disease (Boustani et al., 2003).

Clinical recognition of symptoms. In primary health care settings, clinicians who are performing routine checks on elderly are often encouraged to be alert to the possibility that these patients may show symptoms of dementia. This early awareness is useful and important as the patient’s family can be start treatment and diagnosis for the dementia patient earlier. This will help to reduce the time lag factor between discovery of problem and diagnosis, treatment and support services for the dementia patients (Boustani et al., 2003).

Formulate advance directives. The family may be able to formulate advance directives; choose a person to exercise power of attorney for financial and personal care decision making; consent to participate in research; and contemplate issues such as motor vehicle driving, self-neglect, financial victimization, and housing relocation (Drickamer & Lachs, 1992).

Effective treatment of co-existing conditions. Screening may also permit earlier and more effective treatment of co-existing conditions by improving medication adherence and avoiding drug interactions (Boustani et al., 2003).

Early diagnosis of the illness. Clinicians using history records and physical examination on patients have often failed to detect dementia during their primary care visits. Patients who are suffering from mild and moderate dementia were often not identified. In such situations, screening tests might be useful in identifying people with undiagnosed dementia. Follow-up tests and diagnosis would also permit patients and their families to receive care at an earlier stage before the disease deteriorate further (Jha et al., 2001).

Social benefits to society. A Monte Carlo cost and benefit analysis using estimates of parameters in public medical literature (where the parameters were evaluated using a decision tree analysis) suggests that the initial identification, screening and treatment of dementia have the potential to lead to massive, positive net benefits and savings to society, states and the government (Weimer & Sager, 2009).

Health and psychological benefits to society. Even if early treatment cannot alter the natural history of dementia by preventing or slowing the rate of cognitive decline but health, psychological, and social benefits from early recognition of dementia through education and improved decision may make screening valuable to the caregivers and families (Plassman, Williams, Burke, Holsinger, & Benjamin, 2010).

Connell and Gallant (1996) posited that an understanding of patients' perceptions of the benefits and harms of dementia screening may assist to remove the barriers against screening in primary care. Boustani et al. (2003) also posited that screening has to be accepted by the elderly community before these screening programmes can be implemented in continuous care retirement communities.

Fowler and colleagues (2012) conducted a cross-sectional study of 554 primary care patients aged 65 and older without a documented diagnosis of dementia in urban primary care clinics in the United States from 2008 to 2009. The study team developed and used the Perceptions Regarding Investigational Screening for Memory in Primary Care Questionnaire (PRISM-PC; Boustani, Perkins, Monahan et al., 2008) on these patients. Fowler and colleagues (2012) concluded that individuals who have concerns that dementia screening would be harmful would have higher refusal rates for screening than those who believed that the early detection of dementia through screening would be beneficial. Age and perceived benefit of screening are found to be associated with the acceptance of dementia screening in primary care for elderly aged 65 and older (Fowler et al., 2012).

Literature Review on Benefits and Harms of Screening

United States (U.S) Study. In a U.S study conducted in 2001, the American Academy of Neurology published an evidence-based review of the diagnosis, evaluation, and treatment of dementia (Petersen et al., 2002). Petersen and colleagues (2002) found that, on average, cholinesterase inhibitors produce a small benefit in Alzheimer's disease patients. The conclusion was that insufficient data exist to make any recommendations regarding cognitive screening of asymptomatic individuals. Petersen and colleagues (2002) recommended diagnostic evaluation and monitoring for persons with mild cognitive impairment because of their increased incidence of dementia.

In another study by The U.S. Preventive Services Task Force (USPSTF), Boustani, Peterson, Hanson, Harris and Lohr (2003) found insufficient evidence to recommend for or against screening for dementia. The study team conducted a systematic review of the literature regarding the benefits and the harms of screening primary care populations to detect undiagnosed cases of dementia and found little evidence to support that pre-screening is beneficial to patients who have dementia (Boustani et al., 2003). Both U.S studies found inconclusive evidence that pre-screening is beneficial for elderly people to detect dementia.

Canada Study. Costa and colleagues (1996) found similar conclusion to that in the 1996 practice guideline issued by the Agency for Health Care Policy and Research and to the recommendations of the 2001 Canadian Consensus Conference on Dementia (Patterson & Gass, 2001) in that it recommended a complete evaluation and close follow-up of individuals with memory complaints or functional decline. Although randomized controlled trials may provide greater evidence for treatment of diagnosed disease than have been available heretofore, they do not directly address the issue of screening to promote earlier treatment (Patterson & Gass, 2001).

United Kingdom (U.K) Study. Researchers from the University of Cambridge conducted a medical literature search of 14,000 studies through May 2012 and found scant evidence that it is cost effective to have early screening for dementia. The study concluded that more research has to be done in order to access the benefits as well as potential harms of screening (Collins, 2013).

Costs of screening for dementia in Singapore

The AD8 takes less than 3 minutes to administer to a single informant. Some preliminary research has been conducted in Singapore (Dong et al., 2014), evaluating the feasibility of screening for dementia in a primary healthcare setting at a large Polyclinic (a Singaporean large subsidised public medical clinic). This allows us to estimate the likely costs of introducing such a screening program on a national level in Singapore. Currently, there is no study done on the cost of screening in Singapore. Singapore provides a useful opportunity for such an exploratory analysis, as it is a small country with a network of 18 Polyclinics (National Healthcare Group, 2013; Singhealth, 2014). While calculating the costs of a screening program requires some amount of conjecture, the limited network of Polyclinic in Singapore will allow us to extrapolate the data reported from one Polyclinic by Dong and colleagues (2014) to estimate the costs that would be incurred by running a nationwide screening program.

The total cost would be primarily related to staff time, which was calculated by their salaries. By taking the three -minute time to administer a single AD8 and the typical salary of a nurse practitioner in Singapore, this study can estimate the likely personnel costs of screening. Dong et al. (2014) approached 787 patients, although 115 of these were less than 60 years old, which was the eligibility criterion for the study. Of the other 672, of which 375 were eligible (297 were excluded for other reasons, primarily having no informant). A further 170 refused to participate and 6 of the 205 who consented did not complete the study for other reasons. Thus overall, 199 informants completed the AD8.

For these 199 who complete the AD8, taking 3 minutes each would total 597 minutes of staff time. The current population in Singapore aged 65 and above is 459,715 (Singstat, 2015). Extrapolating the three minutes for AD8 administration to the entire population of individuals aged over 65 would entail a total of 1,379,145 minutes. This is equivalent to 22985.75 hours, or 2704.21 work days (of 8.5 hours per day). Using a 5-day week (polyclinics operate Monday to Friday) as an example, this equates to 2704.21 divided by five, or 540.84 days' work. At 20 days per month, this is 27 months' work.

There are no official figures available for salaries of nurses in Singapore, and the cost of employing a nurse obviously depends on qualifications, experience and seniority, however a figure of SG$2,400 per month was obtained from a group of online consultancy firms. This figure represents a basic rate of pay for an agency nurse. At this rate of pay, the 27 months of salary that would be needed for nurses to screen all older patients in Polyclinics is SG$64,800.

This estimate obviously makes some assumptions, some of which may be unrealistic. For example, this assumes every older person presents to the polyclinic once over the time period of the screening program. This does not allow for any sort of holidays or shift work penalty rates bonuses or allowances for the nurses, nor for any administrative costs of employment. In fact, it does not even allow for any sort of breaks or gaps between assessing patients. This assumes an entry level nurse would be employed to do the task. The number could be an underestimate if there are patients and informants who take longer than the typical three minutes to complete an AD8, for example due to high physical care needs or language issues. Also, suitable reliable informants would not be available for all older people.

An alternative calculation would be the cost of employing one nurse to work in each polyclinic on a full time basis. This gives an estimated SG$518,400 to employ the 18 nurses for one year, or SG$547,200 if one extra nurse is employed.

Clearly these figures are estimates; however, they do demonstrate that the labour costs involved in screening are not prohibitively high. Importantly, this does not include running costs such as the paper (or technology) for the questionnaire, administrative costs and overheads such as utility bills. However, even doubled, the costs involved in screening do not seem to be a significant barrier to establishing a screening program.

The next question is whether such a screening program would have any significant impact on the cost of dementia care. It is noteworthy here, that of the 199 screenings completed by Dong and colleagues (2014) only 59 screened positive as being likely to have dementia or other cognitive disorder. This is a positive screen rate of 29.65%. As noted in Chapter One, the prevalence rate in Singapore of people with dementia aged 65 years and above is about 6.2% (The Alzheimer’s Disease Association, Singapore, 2016). This suggests that many of those who screened positive did not actually have dementia, although some may have had Mild Cognitive Impairment. As only 11 participants out of 59 positive screenings (Dong et al., 2014) accepted a referral for clinical assessment, we cannot say what the actual rate of detection of dementia was. However, the high rate of positive screens highlights the need for follow up clinical assessment services, where the identified patient can receive the comprehensive clinical, neuropsychological and neuro- imaging assessments described earlier in this chapter.

Proponents of screening point to the benefits of earlier diagnosis of dementia and the opportunity for commencing treatment earlier. However, as noted in page 114 of this chapter, there are psychological, medical and social benefits of early dementia recognition. As noted in Chapter Three, the costs of care in dementia were lower for those in milder phases of the disease. Unfortunately, we do not have sufficient information to determine the extent to which screening would actually lead to a full diagnostic assessment. Further, the data cited here does not give us sufficient information to calculate the exact cost savings that could result from maintaining patients with dementia in the milder stages of illness. The referral rate of 18.64% is not encouraging, as only a few participants who screened positive accepted a referral for comprehensive assessment (Dong et al., 2014), and this raises questions about the effectiveness of a screening program in terms of encouraging earlier treatment and subsequent reductions in the costs of care. Perhaps education and public relations on the issues of dementia will encourage higher referral rates. Some systematic method of monitoring these patients could also be implemented, possibly including some incentive for healthcare professionals to do this monitoring.

The findings reported here, when considered in conjunction with the review study from the University of Cambridge cited earlier (Collins, 2013) suggest that it is not the cost of screening that is a concern, but rather it is the effectiveness of screening at identifying cases and leading to clinical assessment that should be the focus of research and discussion. It is beyond the scope of this thesis, which focuses on costs, to explore effectiveness of screening. However, it seems that in the case of Singapore that any national model of screening for dementia needs to include an educational component to encourage patients and their families to follow up any positive screening results and possibly some incentives for healthcare practitioners to monitor this. The accuracy of screening results needs closer attention, given the discrepancy noted between Dong et al (2014) rate of positive screens (29.65%) and the known prevalence rate of dementia in those aged 65 and above in Singapore (6.2% in 2015). The costs of screening, however, would not be a significant barrier to establishing a screening program.

Chapter Six

Conclusions and Implications of Findings

Introduction

In Chapter Six, this study summarises the discussions and findings, and concludes with the implications from each chapter's findings and areas for further research.

Chapter One compared the global population of older people (aged 60 years or over) and their projections over the next 15 years with those of Singapore. The global population of older people (aged 60 years or over) is projected to increase by 55.67% over the next 15 years (World Population Ageing, 2015). In absolute numbers, the number of older persons (aged 60 years or over) globally is expected to increase from 0.90 billion in year 2015 to 1.40 billion in year 2030 and close to 2.00 billion in year 2050 (World Population Ageing, 2015). In Singapore, the percentage of people who are 65 years and above had been increasing steadily by 7.8 percentage points over the last 44 years.

The incidence and prevalence rates of dementia around the world in LMICs and HICs and their projections were compared with those of Singapore. In Singapore, the prevalence rate of people with dementia aged 65 years and above is about 6.2% (Alzheimer's Disease Association, Singapore, 2016) which is slightly below the prevalence rate of PWD in the Asia Pacific region (high income) of 6.54% (World Alzheimer Report, 2015). There are currently 40,000 people with dementia in Singapore and this figure is expected to increase to more than double to 92,000 in year 2030 and 187,000 in year 2050 (Alzheimer's Disease Association, Singapore, 2016). This increase of 130% is very high compared to the estimated proportional increase of 56% for Asia Pacific region (high income) countries forecasted by the World Alzheimer Report (2015). The study also examined the different healthcare systems in HICs and LMICs. HICs have higher rates of dementia mainly because of better technology and medication, which can detect and monitor the progression of the disease. Despite cultural differences in these countries around the world, the types of healthcare systems for PWD and PWOD seem consistent with the presence of DDCCs, DCCs, respite care, and RCFs. Informal care for PWD in the form of employment of FDWs is uniquely a part of Singapore’s culture.

Chapter Two examined literature on the global cost of dementia in HICs and LMICs. PWD are often cared for by their family members at home and these caregivers (mainly the spouse, sibling or children) often describe the caregiving experience as "enduring stress and frustration" (Butcher, Holkup, & Buckwalter, 2001). The literature review of studies by Livingston, Manela and Katona (1996), Murray, Schneider, Banerjee and Mann (1999), Coen, O'Boyle, Coakley and Lawlor (2002) showed evidence of high levels of distress and depression among caregivers of people with dementia, seen especially in many studies of service users and in community surveys. Additional studies (i.e., Buhse, 2008; Stucki & Mulvey, 2000; Zarit, Reever, & Bach-Peterson, 1980) also emphasized the psychological distress of caregiver burden as a result of the experiences in taking care of their loved ones who are unable to provide for themselves. Chapter Two noted that these caregivers may also incur additional out-of-pocket expenses to support a relative with dementia financially. There can also be adverse impacts on their physical health, for example, as a result of the strains of helping an individual to cope with the essential activities of daily living.

The global costs of dementia had increased 35.4% from US$ 604 billion in 2010 to US$ 818 billion in 2015. Of this amount, 22% of the global costs were from the Asia Pacific region. Within the Asia Pacific region, 99.22% of the costs were from ADI members, which are predominately HMICs and LMICs. Asia has the highest global incidence rate for dementia (Alzheimer's Disease International, 2015) with 49% of the total of new cases, with Europe having 25%, Americas having 18% and Africa having 8%.

However, in terms of informal cost of care, HICs incurred 90% of the total global cost. Although most people with dementia live in LMIC, about 90% of these costs were in HIC (Alzheimer's Disease International, 2015). Those LMIC have larger costs associated with informal care for PWD whilst care costs in HIC are relatively evenly distributed across informal and social care (World Health Organization, 2012).

The costs associated with caring for PWDs are also found to be different between countries and dependent upon factors such as urbanization, cultural and family structures, public health infrastructure, care services, gross domestic product, and government (Alzheimer's Disease International, 2014).

Chapter Three compared the informal cost and formal cost of care for PWDs. It also examined the components of formal cost of care, healthcare utilisation and the presence of other chronic conditions that impact the formal cost of care of PWDs. Estimates are calculated for the total cost (formal and informal) of care for PWD in Singapore. Chapter Three also identified risk factors such as age and gender as factors related to informal cost of care for PWDs. To the best of my knowledge, this was the first study that to conduct such a detailed analysis in Singapore. Chapter Three also calculated the cost-values of formal care and medication costs, examined the relationships between informal cost and disease severity of dementia, and evaluated the association of informal cost and PWD's cognitive and functional capabilities. Chapter Three analysed four scenarios of estimating informal cost of care for PWDs: 1) the presence of FDWs and DCCs or DDCCs; 2) the presence of FDWs and no DCCs and no DDCCs; 3) no FDWs and DCCs or DDCCs, and 4) no FDWs and no DCCs and no DDCCs. Chapter Three also explored the differential costs of care (by disease severity) for PWDs using DCCs or DDCCs and employing FDWs, and compared informal cost of care for PWD in Singapore in HICs compared to LMICs.

Chapter Four explored the costs of care for PWODs. This chapter examined the informal costs, in terms of caregiver time, of caring for community-dwelling elderly individuals without dementia. Chapter Four then provided some comparisons of these costs for PWODs with those costs found for PWDs in Chapter Three. The comparison of informal cost of care by disease severity (none, mild, moderate and severe) was also examined in Chapter Four. This included a comparison of the impact of having FDWs on the informal cost of care for PWODs compared to PWDs, and a comparison of support provided by family caregivers of PWODs and PWDs.

Chapter Five provided estimates of the cost of dementia screening in primary care in Singapore. Costs are often cited as a barrier to screening programmes, yet screening programmes have the potential to influence total costs of dementia care.

Summary of findings

The study main findings were: 1) the mean annual cost of informal care for PWD in Singapore was 1.7 times higher than cost of formal care; 2) the mean annual informal cost of care was 2.3 times higher than full time cost in RCFs; 3) the formal cost of care was highest for PWDs in RCFs, DCCs, DDCCs and the direct medical cost (dementia); 4) informal cost of care for PWDs was the highest (63%), followed by direct social costs (33%) and direct medical cost (includes dementia and non-dementia medications (4%); 5) the annual costs of informal care for dementia care increased with disease severity; 6) for each higher value of CMMSE, the informal cost of care is reduced by SG$1,173.94; 7) there was no significant association between annual cost of informal care and functional abilities; 8) the mean annual informal cost of care in Singapore is comparable with those in developed countries like the United States, United Kingdom and Japan; 9) the informal cost of care for those with dementia did not vary much with or without the use of DCCs or DDCCs; 10) the costs for those who did not have FDWs was approximately more than double the costs for those with FDWs; 11) PWDs also suffered from an average of five other chronic health conditions; 12) the most common chronic conditions reported by these PWDs were hypertension, hyperlipidemia, diabetes mellitus and ischemic heart disease; 13) the most commonly reported medications for patients with other chronic conditions included antipsychotics agents, antihypertensive agents and medications for dyslipidemia; 14) about three-fifths of PWDs had FDWs compared to less than a fifth of those PWODs; 15) the mean annual informal cost of care for PWOD was SG$ 5,477.03 while those PWD was SG$ 44,530.55; and 16) the cost of a screening programmes in polyclinics for all PWDs was SG$64,800 (one-time) or estimated SG$518,400 to employ 18 nurses once a year or SG$547,200 if one extra nurse is employed.

Findings and Implications for Research

Comparison of the informal cost and formal costs for caring for PWD

This study indicated the mean total annual cost per participant for this sample was SG$70,184.66. Of this total cost, SG$44,530.55 (63.45%) was attributable to informal cost of care, and SG$25,654.11 (36.55%) was attributable to formal cost of care. As hypothesised, informal cost of care for PWDs was found to be higher than formal cost of care for PWDs. The mean annual cost of informal care in Singapore was 1.67 times higher than formal cost of care.

Implications. The informal cost of care is twice as high as the formal cost of care in Singapore. This is mainly due to the high wages accrued to employed workers in Singapore. The primary caregivers in this study were mainly employed or retired, and the monetary value of work forgone was a major contributor to costs of care. Some of this informal cost could be dissipated through cheaper modes of labour, such as employment of FDWs or the development of more subsidised public DCCs, DDCCs or RCFs, which will be explored later in this chapter.

Examination of the components of formal cost of care

The mean monthly cost of formal care was SG$2,137.84. The largest component was the mean monthly charges for full time RCFs, which was SG$1,603.11 after subsidy (before subsidy SG$2,385.22). The next largest component was the mean monthly charge for DCCs or DDCCs was SG$326.27 after subsidy (before subsidy SG$960.00), followed by the mean monthly cost for direct medications, which was SG$108.66 (SG$201.19 for mean monthly cost for dementia drugs and SG$ 57.38 for mean monthly cost of non-dementia drugs per patient). The subsidy given by the government for non-dementia medications is dependent on many factors; some of these include the income level of the family, condition of the patient and the type of accommodation, but is not applicable to dementia medications. The mean monthly non-medication equipment cost (e.g. walking frames, pacemakers, continence management) for dementia patients was SG$84.20. Full time RCFs costs, when applicable, were the most expensive in nominal terms of all the formal costs, constituting about 73% of total formal costs, however it was still less expensive then informal costs. The mean annual informal cost of care was 2.3 times higher than full time cost in RCFs.

Implications. There are currently three government funded service providers for DDCCs in Singapore (Agency for Integrated Care, 2016). They are New Horizon Centre, Sunlove and Sunshine Welfare Action Mission Home. Estimated charges (before means testing) for these government funded service providers ranged from SG$700 to SG$950 (excluding transport). The amount of government subsidy available for use of these services is dependent on family household income and ranges from 55% for permanent residents, to 80% for Singapore citizens (Agency for Integrated Care, 2016). There are also private operators for DDCCs, DCCs and stay-in RCFs in the Central (22 operators), East (7 operators), North-East (6 operators), North (8 operators) and West (12 operators) zones in Singapore. Caregivers interviewed for the study reported in Chapter Three mentioned the long waiting period for a PWD to be admitted to a DDCC, DCC or RCF, which can be between six months to 24 months. They noted a lack of a common channel to address their concerns on costs and procedures. For some families without any means to afford FDWs or any extended help, this is a long and painful wait. This suggests a possible direction for future research. A study would be useful to explore feasibility of more government funded DDCCs, DCCs and RCFs in selective low and middle income districts of Singapore. Research could also explore the optimal number or ratio of elderly to nurses in each of these DDCCs, DCCs and RCFs in each zone, so that quality care can be provided to the elderly with dementia. Transportation difficulties, inefficiency of care providers, long waiting lists for DCCs, DDCCs and RCFs, stigmatization and lack of awareness are some concerns raised by caregivers in accessing these services. Easy access via more public mode transportation and a common channel or agency to address their concerns can be explored for caregivers to DDCCs, DCCs or RCFs.

Examination of Healthcare Utilisation and other chronic health conditions and formal cost of care of PWD

Out of 51 PWDs, 13 patients (25.49%) were receiving drug therapy for dementia, including donepezil (n = 8), rivastigmine (n = 3), and memantine (n = 2). The mean number of other health problems reported for PWDs was 5 (SD = 2.73). The most prevalent other chronic conditions reported by these patients with dementia were hypertension (62.75%), hyperlipidemia (52.94%), diabetes mellitus (25.49%), ischemic heart disease (15.69%), benign prostatic hyperplasia (13.73%) and anemia (13.73%). The most commonly reported medications for patients with other chronic conditions included antipsychotics agents (48.4%), antihypertensive agents (31.3%) and medications for dyslipidemia (14.1%). Both past and recent studies have found that diabetes, hyperlipidemia, hypertension, cardiovascular disease, obesity, depression, smoking and cognitive inactivity are each associated with an increased risk of developing dementia (Barnes & Yaffe, 2011; Farrow and O’Connor, 2012). Higher cholesterol levels are associated with increased risk for cognitive dysfunction (Yaffe, Fox and Newcomer, 2002)

In the Kaiser Permanente study, those with hypertension at mid-life had a 24% greater risk for Alzheimer's disease (Whitmer, Sidney, Selby, Johnston, & Yaffe, 2005). The Honolulu-Asia Aging study noted that those with borderline high blood pressure had more than three-fold increase in risk for Alzheimer's disease (Launer et al., 2000). Cukierman, Gerstein and Williamson (2005) and Coker and Shumaker (2003) posited that diabetes/obesity predisposes people to heart disease and type 2 diabetes associated with increased risk of cognitive impairment, which is associated with Alzheimer's Disease.

Implications. There are no guarantees that an individual will not develop dementia in his or her lifetime. Dementia cannot be cured but the progression of its stages can be delayed by medication and lifestyle management. However, there are recommendations that can be provided on how best to lower an individual's chances of developing dementia. Many of the risk conditions mentioned above are treatable including diabetes, depression, hypertension, hyperlipidemia, cardiovascular disease, obesity, depression and smoking, highlighting the importance of identification and management of these conditions.

Given that the onset of dementia is frequently before the age of 60, the elderly who are 55 years old and above and diagnosed with other chronic conditions such as hypertension, hyperlipidemia and diabetes mellitus could be referred by their doctors at Polyclinics to go for subsidized basic screening tests of dementia (such as the AD8 or MMSE as discussed in Chapter Five) in government funded hospitals. Currently, there is a lack of standard practices and procedures in administrating screening tests to detect the onset of dementia in its early stages. Further research can explore having a standardized practice of screening for early detection of dementia and quantifying the different stages of the disease and importantly, ensuring follow-up assessment and care after screening.

Valuing Formal Care and Measuring Medication Cost

There were also some formal costs considered in this study. The mean annual cost of full time RCFs for nine patients with severe dementia was SG$19,237.33. Medication costs for dementia-related medications were incurred by 25.49% of that sample, and non-dementia related medications by 74.51% of the sample. The actual costs of non-dementia medication reported by the caregivers was relatively low (at a mean annual cost of SG$ 688.52). This was mainly because the majority of these patients were on the civil service scheme in which costs of drugs are fully subsidised by the government or are deducted from the patient's Medisave medical account. Hence, there is no reportable out of pocket expense to the caregiver. In addition, Singapore has a Pioneer Generation scheme, which heavily subsidises services to all older Singaporeans, thus minimising reportable costs of non-dementia medications.

However, the cost of all the dementia medications in Singapore (i.e., donepezil, rivastigmine and memantine) are not subsidised by the government, which accounts for the high mean annual caregiver-reported costs of these dementia drugs of SG$2,414.24. Some of these PWDs had more prominent behavioural and psychological symptoms of dementia secondary to dementia, rather than cognitive symptoms and, hence, were not on any dementia medications. Some of these PWDs had no other chronic health problems and thus no reportable medication costs. There were also other patients who were not on medications despite having other chronic health problems (such as diabetes mellitus) as these conditions were controlled by methods such as diet and exercise.

Implications. In this study, 25.49% of PWDs were on dementia medications and 74.51% were on non-dementia medications. Yet, the mean monthly cost for dementia drugs was SG$201.19, while the mean monthly cost for non-dementia medication was lower at SG$57.38. However, this figure is a mean cost, and as some of PWDs were not on dementia medication, the costs to those who are using medication are significantly higher. Importantly, the costs of dementia drugs are currently not subsidised by the government in Singapore. These dementia drugs used by the sample reported in Chapter Three are costly and are currently one of the top three costs for these patients. The cost for dementia medication is the third largest component (5.10%) of mean annual formal cost of care for PWD, after RCFs (72.91%) and DCCs (14.84%). There are other patients who need these dementia drugs but are not prescribed because of the high cost. The government may consider channelling resources to partially subsidise or moderate these costs of dementia drugs so that they are accessible to more patients with lower income levels who have dementia but cannot afford to buy them.

Examination of the relationships between informal costs and disease severity

To date, the only other data of costs of informal care in Singapore is provided by Chong and colleagues (2013), who reported median annual costs of SG$15,750 for those with mild dementia and SG$33,408 for moderate dementia. This study showed quite similar costs, at SG$13,847.86 for mild dementia, and SG$38,607.84 for moderate dementia. However, this study has also estimated median annual costs of informal care for severe dementia, at SG$48,727.91, and further demonstrated that the informal costs of care rise with the severity of cognitive impairment, rather than functional impairment, of the patient. For each higher value of CMMSE, the informal cost was lowered by SG$1,173.94. The median annual informal cost of care was the highest when the patients had severe dementia.

Implications. The patients with severe dementia incurred the highest cost of informal care. None of this subgroup employed FDWs as all nine are in long term RCFs. As identified by Tew and colleagues (2010), caregivers will only place their relative with dementia in RCFs as a last resort if there are no FDWs to assist with care or their primary caregivers are employed. In view of this, it would seem logical to explore various forms of subsidies to be extended to elderly persons with severe dementia for the employment of FDWs, possibly based on selective criteria such as the employment status and income status of their primary caregivers. Informal caregivers and family members may experience guilt and other psychological stress after the placement of their loved ones in RCFs (Tew el al., 2010). Further studies can be conducted on ways to explore how to manage these aftermath guilt and stress experienced by these informal caregivers.

Examination of the association of informal costs with cognitive and functional capabilities of PWD

The study on the costs function model showed there was no significant association between annual cost of informal care and functional capabilities; however, there was a relationship of costs and cognitive ability. This association mirrors the higher costs for those with more severe dementia.

Implications. The decline of an elderly person’s functional abilities will also impose stress on caregivers and family members. More care is required and costs to the caregiver increase accordingly. The need for a systematic defined treatment and management of care system for each stage of dementia needs to be explored, to provide appropriate services to these PWODs and PWDs.

Analysis of impact of RCFs and FDWs on informal cost of care for PWD and PWOD

PWDs are typically either at full time RCFs, or cared for at home (HC) by full time FDWs, with primary caregiver support, in Singapore. Some of PWDs may spend half a day at DCCs or DDCCs and be cared for by FDWs at night. It is a common practice in Singapore for households to employ full time live in FDWs to care for elderly relatives with severe dementia at home. These FDWs often have the dual roles of assisting with the household chores as well as taking care of the elderly person with dementia. These FDWs are expected to provide 24/7 care for the elderly family members as part of their duties (Yeoh & Huang, 2010). In some cases, FDWs are the main or sole caregivers for these elderly with dementia, for example when the primary family caregiver also has health problems.

A very small proportion of our sample of PWDs was in RCFs (17.65%), and this reflects the cultural tendency to keep patients at home as long as possible. This is mainly due the Chinese cultural belief of filial piety where it is the responsibility of the children to care for their elderly parents (Yeoh & Huang, 2010). It seems likely that the presence of FDWs enables this approach to care by reducing the time and financial costs of keeping the patient at home. Some primary caregivers employed FDWs (14.60%) in their households for PWODs. The main responsibilities of these FDWs were to do housekeeping chores for these families. However, more than half of the households (58.82%) had employed FDWs for providing direct care to PWDs.

Tew et al. (2010) found that caregivers without FDWs were more likely to place the PWDs in RCFs. This study showed similar results as all PWDs who stayed in RCFs did not have any FDWs at home. In addition to the factors affecting placement in RCFs identified by Tew et al. (2010), the present study also found that PWDs who were in RCFs all had severe dementia.

Implications. Currently in Singapore, the training and consultancy arm of Alzheimer's Disease Association (ADA), ARTC provides training programmes for family caregivers and FDWs to aid them in caring for the PWDs at home (Alzheimer's Disease Association, Singapore, 2016). Many of these caregivers have insufficient education, low literacy skills and may speak only dialects, and thus may not be aware of or able to participate in these training programmes. Hence, many of them are not well prepared from a cultural or educated perspective to understand the disease, and thus develop negative perceptions about dementia and PWDs. Reaching out to this group of caregivers through mass public education or annual campaigns at Polyclinics is one way of exploring means to help them. Attitude and awareness toward dementia through education is one way to enable them to understand the disease better. It would be helpful to caregivers if nurses deployed at Polyclinics were able to speak local dialects besides Mandarin (Chinese) in order to reach out to this group of caregivers who have little or no education. Otherwise, they risk being stuck in a vicious cycle of poverty without the means to assist their loved ones with dementia. Besides awareness and education of the disease, ways to explore adequacy of information resources on dementia, caregiving and funding availability to caregivers should also be made known to the masses.

Analysis of FDWs on informal cost of care for PWDs and PWODs

A study by Tew et al. (2010) concluded that most of caregivers preferred to care for their loved ones in their own homes (HC) than to place them in RCFs. This is possibly because Singapore is still a very much traditional society that considers filial piety and fidelity among the highest values in this Asian state (Tew et al., 2010). This also explained the low figure of 14.3% of caregivers who expressed their desire to place their loved ones in RCFs here.

This study showed similar results to those by Tew et al. (2010) where caregivers preferred to have FDWs to care for their loved ones with dementia at home (58.82%) than in RCFs (17.65%). The presence of a dedicated caregiver is often the fundamental requisite of keeping a loved one with dementia at home (Banerjee et al., 2003).

Implications. This study concluded that having FDWs in the household to care for elderly people with or without dementia is a unique way in Singapore to distribute the informal cost of care for caregivers. Households prefer to have their loved ones with dementia to be cared for at home by FDWs if they can afford them, rather than placed in RCFs (Tew et al., 2010). This thesis has further demonstrated in this study that having FDWs to care for PWDs also halved the informal costs for family household compared to those without FDWs. Policy makers can explore further faster and cost effective schemes for these FDWs solely to be deployed in family households with PWDs. However, it is difficult to ensure that the FDWs are actually full time taking care of PWDs as many households here would also expect FDWs to handle the household chores for the family.

Importance of support by family caregivers

In this study, more than three quarters of the caregivers (83.21%) stayed with PWODs and more than half (54.90) stayed with PWDs. In Singapore, close to 95% of older people co-reside with family members, highlighting the importance of community support by family caregivers (Mehta, 2005).

Implications. In order to provide support for these family caregivers, policy makers need to identify some of the main problems they face in providing caregiving to

PWDs. Primary caregivers who are main pillars for PWDs often expressed concern about the high burden of caregiving while looking after the elderly with dementia, especially as the disease progresses. Employed informal caregivers often experienced the difficulty of balancing work with caregiving for their loved ones as well as the emotional burden of stress of being the primary caregiver in the family. The cost of caregiving such as the time taken off to bring the PWDs for hospital visits and check-ups also had an emotional burden on these primary caregivers. Ways to reduce the high caregiver burden for caregiving can be explored. A benefits and rewards scheme can possibly be set up.

Analysis of impact of DCCs on informal cost of care for PWD

The informal cost of care for those with dementia did not vary much with or without the use of DCCs or DDCCs. However, the costs for those who did not have FDWs was approximately more than double the costs for those with FDWs. Ceterius paribus, results from this study showed that there were cost savings in care of PWDs when the family employed live-in FDWs.

These findings were consistent for both patients with mild, moderate and severe dementia and for those who did or did not use DCCs or DDCCs. Families in Singapore often employ a full time live-in FDW, to reduce the burden of care by the primary caregiver, and this study showed that this is reflected in reduced costs of care where FDWs are employed. When the primary caregiver was unable to assist the PWD, this time taken to care for the patient was commonly replaced by the FDW.

Implications. Ways to explore the high expenditures for DCCs, DDCCs and RCFs can be explored further.

Comparison of informal cost of care in Singapore versus the HIC and LMIC

This study compared informal cost of care for PWD in Singapore and HICs such as the United States of America (USA), United Kingdom (UK) and Japan and LMIC in Turkey. This gives an indication how costs of dementia care in Singapore compare to those found around the world.

This study showed median annual informal cost of care at US$9,891.33, US$27,577.03 and US$34,805.65 for mild, moderate and severe dementia in Singapore which are comparable to those reported in the European and USA studies of US$9,950, US$18,385 and US$57,937 for mild, moderate and severe dementia respectively (Gustavsson et al., 2010; Moore, Zhu, & Clipp, 2001). This is despite the prevalence of employment of FDWs in the provision of informal care of the patients when they were fully or partially staying at home.

The mean annual informal cost of care in 2015 at US$31,807.78 in Singapore is comparable to those in developed countries of the United States, US$49,843.29, in 2015 dollars (Hurd et al., 2013), United Kingdom, US$51,894.86, in 2015 dollars (Torjesen, 2014), and Japan, US$31,675.64 (International Conference on Cognitive Decline and Its Economic Consequences in Japan, 2015). Turkey, being a developing country, had a relatively low mean annual informal care cost of US$5,327 (Zencir *et al.,* 2005), in 2015 dollars compared to Japan, Singapore, United Kingdom and United States.

Implications. There is currently a lack of a proper framework for the identification or early detection of dementia to the placing of PWDs in RCFs. Policy makers can explore the possibly of setting up a proper national channel, portal or framework where caregivers can access all the information to address their concerns of care and management of their loved ones with dementia.

Factors related to informal cost of care

Study 1 hypothesized that the informal cost of care would increase with age, cognitive decline and functional decline, and be higher for females before age of 75 years. The negative correlation between the informal cost of care and age is due to the profile of PWODs in a community dwelling environment. These PWODs were at the polyclinic with more than a quarter (26.31%) incurring no informal cost of care as they are totally independent, with zero scores on measures of ADL, IALD and supervision time by their caregivers. These PWODs were mainly at the polyclinic for their annual check-up or follow-up with their doctors, and the caregiver/informants do not spend significant time caring for these generally healthy PWODs, hence incurring minimum cost. Findings from this study also showed that PWODs tends to have higher costs if their dependence level on the caregiver is high.

This study showed that the mean cost of care across the lifespan is higher for a typical female than a typical male. The mean cost of care for a female during the lifespan below the age of 75 is SG$511.84 while that for a male is SG$415.76. This is quite likely due to the child bearing period for the female (Forget at el., 2008). Similarly, the cost of care for a female above the age of 75 years is also higher at SG$444.99 than a typical male at SG$279.96 as a female life expectancy is almost six years longer than the typical male, thus older females may be increasing this average cost (Forget at el., 2008). Women are also generally more health conscious, seeking help for health concerns throughout the lifespan than men (Smith, Mayer, & Wittert, 2006). Smith, Mayer and Wittert (2006) also noted that the health of men is poorer than that of women, mortality rates are higher and men use health services less often than women.

The informal cost of care for PWDs showed a positive correlation with age and for female above 75 years. The positive correlation is due to the profile of PWDs who mostly have severe dementia (82.35%). All PWDs with severe dementia interviewed were in a mental public health institution.

Implications. Age and gender are two contributing factors to high informal cost of care for PWDs in our study. Further research can be conducted on ways to implement a proper framework for dementia care system or management in Singapore, such as encouraging females above 65 years to go for pre-dementia screening, and subsidies to be given, similar to the current system for breast cancer and cervix cancer screening for females in Singapore, presently.

Examination of informal cost and the cost of screening

In order to find out if cost is a barrier to screening for elderly who are 65 years and above, this study estimated the cost of a one-time off screening by employing a nurse at polyclinics for these elderly in a public health institution or Polyclinic. The salary that would be needed for nurses to screen all older patients in Polyclinics is SG$64,800. An alternative calculation would be the cost of employing one nurse to work in each polyclinic on a full time basis. This gives an estimated SG$518,400 to employ the 18 nurses for one year, or SG$547,200 if one extra nurse is employed.

Implications. An understanding of patients' perceptions of the benefits and harms of dementia screening may shed light on the barriers and possible facilitators to implementing dementia screening programs in primary care (Boustani et al., 2003; Connell & Gallant, 1996). In addition, it may facilitate the development of patient-oriented decision aids and educational programs that could reduce the negative effect of early dementia detection on patients and their family members (Boise et al., 2010;

Carpenter et al., 2008). The implementation of a screening program to detect dementia and the different stages of the disease can be explored. However, more important, is the follow-up assessment after the screening.

Estimation of informal costs of care for PWDs in a private community-setting versus PWODs in a community dwelling

Study 2 of this thesis compared the data of PWODs to that of Chapter Three for PWDs. It was hypothesised that the costs for this sample of PWODs will be lower than the costs identified for the sample of PWDs in Chapter Three. This study found that the mean annual informal cost of care for PWODs was SG$ 5,477.03 while those PWDs was SG$ 44,530.55. This difference was not unexpected as care for PWDs generally required more time due to their cognitive impairment and functional disability compared to those PWODs. The difference between the two samples is striking. Despite recruitment from different sources for the two samples, these data provide clear evidence of the high costs of informal care for PWDs as compared to PWODs.

Implications. The provision of adequate infrastructure and resources in terms of more satisfactory home and respite care options, sufficient intermediate care facilities, adequate dementia beds in nursing homes and adequate capacity of memory clinics are ways to distribute some of this high informal cost from caregivers for PWDs.

Total Cost of Care of Dementia in Singapore

There are currently about 40,000 people with dementia in Singapore (Alzheimer's Disease Association, Singapore, 2016), which is costing the government SG$2.81 billion annually. By 2030, that number is expected to rise to 92,000 (Alzheimer's Disease Association, Singapore, 2016). This will cost the government healthcare expenditure to escalate almost triple to SG$ 6.46 billion, of which SG$4.10

billion will be attributable to informal cost of care and SG$2.36 billion to formal cost of care for PWD in Singapore.

Implications. Dementia is not only a medical economic problem, it is also a societal problem. Dementia is a national health priority (World Health Organisation, 2015). Cost is a major and real concern for informal caregivers of PWDs. The government can explore a national dementia plan as a national priority in Singapore in terms of a proper economic, social and legal framework to assess, assist and judge the resources, benefits and capabilities of PWDs. The establishment of a well-defined legal framework is crucial in determining matters related to PWDs assets and monies.

Currently, many caregivers with PWDs interviewed in our study sample were not aware of the legal procedures to plan for their loved ones with dementia if the disease deteriorates. Many only know of the Power of Attorney (LPA) and Advanced Medical Directives (ADM). More options can be explored for these caregivers of PWDs.

Recommendations

On a macro-perspective, the population in the Asia Pacific region is currently almost half of the world’s population. The number of PWDs living in this region is estimated to triple between now and 2050. There is an urgent need for governments to ensure that there are policies and plans with adequate care and services provided to PWDs and their caregivers. It is recommended that all Asia Pacific governments consider and adopt the updated 2004 Kyoto Declaration, according to their own country demographic, cultural and health care contexts, while non-government organizations and other stake holders be encouraged to participate actively. Table 23 summarizes the key 10 recommendations.

Table 23

Kyoto Declaration: Minimum Actions required for the Care Of People with Dementia (Alzheimer's Disease International, 2006)

Ten overall recommendations	Scenario A Low level of resources	Scenario B Medium level of resources	Scenario C High level of resources
1. Provide treatment in primary care	Recognize dementia care as a component of primary health care. Include the recognition and treatment of dementia in training curricula of all health personnel. Provide refresher training to primary care physicians (at least 50% coverage in 5 years).	Develop locally relevant training materials. Provide refresher training to primary care physicians (100% coverage in 5 years).	Improve effectiveness of management of dementia in primary health care. Improve referral patterns.
2. Make appropriate treatments available	Increase availability of essential drugs for the treatment of dementia and associated psychological and behavioral symptoms. Develop and evaluate basic educational and training interventions for care givers	Ensure availability of essential drugs in all health care settings. Make effective care giver interventions generally available.	Provide easier access to newer drugs (e.g. anticholinesterase agents) under public or private treatment plans.
3. Give care in the community	Establish the principle that people with dementia are best assessed and treated in their own homes. Develop and promote standard needs assessments for use in primary and secondary care. Initiate pilot projects on development of	Initiate pilot projects on integration of dementia care with general health care. Provide community care facilities (at least 50% coverage with multidisciplinary community teams, day care, respite and inpatient units for	Develop alternative residential facilities. Provide community care facilities (100% coverage). Give individualized care in the community to people with dementia.

	multidisciplinary community care teams, day care and short term respite. Move people with dementia out of inappropriate institutional settings.	acute assessment and treatment). According to need, encourage the development of residential and nursing home facilities, including regulatory framework and system for staff training and accreditation.	
4. Educate the public	Promote public campaigns against stigma and discrimination. Support nongovernmental organizations in public education.	Use the mass media to promote awareness of dementia, foster positive attitudes, and help prevent cognitive impairment and dementia.	Launch public campaigns for early help-seeking, recognition and appropriate management of dementia.
5. Involve communities, families and consumers	Support the formation of self-help groups. Fund schemes for nongovernmental organizations.	Ensure representation of communities, families, and consumers in policymaking, service development and implementation.	Foster advocacy initiatives
6. Establish national policies, programs and legislation	Revise legislation based on current knowledge and human rights considerations Formulate dementia care programs and policies. - Legal framework to support and protect those with impaired mental capacity - Inclusion of people with dementia in disability benefit schemes - Inclusion of care givers in compensatory	Implement dementia care policies at national and sub national levels. Establish health and social care budgets for dementia care. Increase the budget for mental health care.	Ensure fairness in access to primary and secondary health care services, and to social welfare programs and benefits.

	benefit schemes Establish health and social care budgets for older persons.		
7. Develop human resources	Train primary health care workers. Initiate higher professional training programs for doctors and nurses in old age psychiatry and medicine. Develop training and resource centres.	Create a network of national training centres for physicians, psychiatrists, nurses, psychologists and social workers.	Train specialists in advanced treatment skills
8. Link with other sectors	Initiate community, school and workplace dementia awareness programs. Encourage the activities of nongovernmental organizations.	Strengthen community programs.	Occupational health services for people with early dementia. Provide special facilities in the workplace for care givers of people with dementia. Initiate evidence-based mental health promotion programs in collaboration with other sectors.
9. Monitor community health	Include dementia in basic health information systems. Survey high-risk population groups.	Institute surveillance for early dementia in the community.	Develop advanced monitoring systems. Monitor effectiveness of preventive programs
10. Support more research	Conduct studies in primary health care settings on the prevalence, course, outcome and impact of dementia in the community.	Institute effectiveness and cost-effectiveness studies for community management of dementia.	Extend research on the causes of dementia. Carry out research on service delivery. Investigate evidence on the prevention of dementia.

On a micro-perspective, going forward, further research can be conducted on developing a broadly defined framework to possibly include policies for implementation of education and awareness campaigns on the prevalence of dementia. This should be tailored to matured estates where the ageing populations are higher. Work must also explore subsidy or moderation for dementia medications, more funding mechanisms for enrolment into DDCCs, DCCs, and RCFs, better integration of care management and services, expanding specialty services. The move towards more centralised screening and diagnostic facilities and memory clinics island-wide would be beneficial, with improved training for health care professionals and caregivers and families. Finally, some rewards scheme for informal caregivers and strengthening and expanding of the existing infrastructure for quality health care services for PWDs may assist Singapore transition towards a more holistic model for the population to anticipate a brighter future as it increases its life expectancy.

Conclusion

This thesis aimed to calculate the cost of total cost of care (including formal and informal cost of care) for PWDs and PWODs in Singapore. The main hypotheses were that the cost of informal cost of care for PWDs was higher than PWODs and cost of informal care increased with disease severity.

Chapter 1 and Chapter 2 started with an introduction on aims of this study and literature review of the global cost of care for PWDs respectively. Chapter 3 and Chapter 4 were findings drawn from two field studies of PWDs and PWODs from different settings. The RUD questionnaire, Barthel Index and CMMSE, MMSE were administered to PWDs and PWODs to capture the formal and informal cost of care for them. Findings from both studies were compared and summarized in Chapter 4 (pages 128-129). It is worthwhile to highlight some of the key findings here. They included the annual cost of informal costs of care was 1.7 times higher than the annual formal cost of care; cost of informal care increased with the severity of the disease; for each higher value of CMMSE, the informal cost of care is reduced by SG$1,173.94; there was no significant association between annual cost of informal care and functional abilities; the informal cost of care for those with dementia did not vary much with or without the use of DCCs or DDCCs; the costs for those who did not have FDWs was approximately more than double the costs for those with FDWs; PWDs also suffered from an average of five other chronic health conditions; the mean annual informal cost of care for PWOD was SG$ 5,477.03 while those PWD was SG$ 44,530.55. Chapter 5 covered literature review on screening with the objective to find if cost is a barrier to screening in Singapore. The objective was to calculate the cost of screening in Singapore. The finding was the cost of a screening programme in polyclinics for all PWDs was SG$64,800 (one-time) or estimated SG$518,400 to employ 18 nurses once a year or SG$547,200 if one extra nurse is employed.

Singapore has always values the importance of human capital in a tight labour economy here. With a longer life expectancy of the elderly population here, it makes sense for households to employ FDWs to care for PWDs as the cost of employing a FDW to care for PWD is half of those without FDWs. This will free up the human capital of employed persons to return to workforce and contribute to the economy.

In conclusion, this thesis has identified the costs components of caring for PWDs (including dementia drugs, RCFs, DCCs, informal cost of care) in Singapore, factors affecting the elderly healthcare expenditure here (vis-à-vis USA, UK, Europe, Japan, Canada and Sweden), and measures that could be implemented to reduce the burden of caregiving and cost of caring on families of PWDs here. Moving forward, the findings from these studies on costs of care for PWDs and PWODs can be utilized for further studies for healthcare expenditure planning by the government and policy makers in helping the caregivers and families of PWDs in Singapore.

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THE RESOURCE UTILIZATION IN DEMENTIA (RUD) QUESTIONNAIRE
BASELINE QUESTIONNAIRE

A1. CAREGIVER
A1.1 Description of Primary Caregiver

1 Age ______ years

2. Sex:
   1. Male ☐
   2. Female______________ ☐

3. Relationship to patient:
   1. Spouse ☐
   2. Sibling ☐
   3. Child ☐
   4. Friend ☐
   5. Other _______________ ☐

   (Staff not allowed)

4. Number of children currently living with you:

   _______ child(ren)

5. Do you live with the patient?
   1. Yes ☐
   2. No ☐

6. How many other caregivers are involved in the care?
   - 0 ☐
   - 1 ☐
   - 2 ☐
   - 3 ☐
   - 4 or more ☐

7. Among all caregivers what is your level of contribution?
   1. 1-20% ☐
   2. 21-40% ☐
   3. 41-60% ☐
   4. 61-80% ☐
   5. 81-100% ☐

A1.2 Caregiver Time

1. On a typical care day during the last 30 days, how much time per day and night did you spend asleep?

|__|__| hours and |__|__| minutes per day and night

2a). On a typical care day during the last 30 days, how much time per day did you assist the patient with tasks such as toilet visits, eating, dressing, grooming, walking and bathing?

|__|__| hours and |__|__| minutes per day

2b). During the last 30 days, how many days did you spend providing these services to the patient?

|__|__| days

3a). On a typical care day during the last 30 days, how much time per day did you assist the patient with tasks such as shopping, food preparation, housekeeping, laundry, transportation, taking medication and managing financial matters?

|__|__| hours and |__|__| minutes per day

3b). During the last 30 days, how many days did you spend providing these services to the patient?

|__|__| days

4a). On a typical care day during the last 30 days, how much time per day did you spend supervising (that is, prevent dangerous events) the patient?

|__|__| hours and |__|__| minutes per day

4b). During the last 30 days, how many days did you spend providing these services to the patient?

|__|__| days

A1.3 Caregiver Work Status

1. Do you currently work for pay?
   1. Yes ☐ If **yes**, answer questions 3 to 5
   2. No ☐ If **no**, answer question 2 **only**

2. Why did you stop/reduce working?
   1. Never worked ☐
   2. Reached retirement age ☐
   3. Early retirement (not disease-related) ☐
   4. Laid off ☐
   5. Own health problems ☐
   6. To care for patient ☐
   7. Other ____________________ ☐

3. How many hours do you work in total for pay per week?

   |__|__| Hours per week ☐ None

4. Of this number of hours, how many hours per week are you paid to care for the patient?

   |__|__| Hours per week ☐ None

5. During the last 30 days, by how many hours have you cut down on the number of hours that you usually work each week because of your caregiving responsibilities?

   |__|__| Hours per week ☐ None

6. During the last 30 days, please specify the number of times that your caregiver responsibilities affected your work in the following ways.

   A. Missed a whole day of work

   |__|__| Number of times ☐ None

   B. Missed a part of a day of work

   |__|__| Number of times ☐ None

A1.4 Caregiver Health Care Resource Utilization

1. During the last 30 days, how many times were you admitted in a hospital (for more than 24 hours)?

└──┴──┘ Number of times ☐ None

2. If you were admitted in a hospital during the last 30 days, please specify the total number of nights spent in each type of ward.

Ward	Number of nights during the last 30 days
Geriatric	
Psychiatric	
Internal medicine	
Surgery	
Neurology	
General ward	
Other (please specify)	

3. During the last 30 days, how many times did you receive care in a hospital emergency room (for less than 24 hours)?

└──┴──┘ Number of times ☐ None

4. During the last 30 days, consider how many times you visited a doctor, physiotherapist, psychologist or other health care professional. Please specify the number of visits for each type of care received.

☐ I did not visit any of these health care professionals during the last 30 days

Type of care	Number of visits during last 30 days
General practitioner	
Geriatrician	
Neurologist	
Psychiatrist	
Physiotherapist	
Occupational therapist	
Social worker	
Psychologist	
Other (e.g. specialist; please specify)	

5. Please specify what medications you are currently taking (prescription or over-the-counter).

☐ I am not taking any medications currently

Name of medication	Strength (mg)	Number of times per day	Number of days taken in the last 30 days

A2. PATIENT

A2.1 Patient Living Accommodation

1. Please specify the patient's current living accommodation.

1. Own home (owner occupied or rented) ☐
2. Intermediate forms of accommodation (not dementia-specific) ☐
3. Dementia-specific residential accommodation ☐
4. Long-term institutional care* ☐
5. Other ______________________________ ☐

*If nursing home accommodation is permitted at baseline, otherwise this alternative should be deleted

2. Who does the patient live together with?

1. Alone ☐
2. Spouse ☐
3. Sibling ☐
4. Child ☐
5. Other ☐
6. Not applicable__________ ☐

3. During the last 30 days, if the patient temporarily changed living accommodations (i.e. moved to a new location for more than 24 hours and then back to the original location), please specify the number of nights spent in this temporary living accommodation.

	Number of nights
1. Own home (owner occupied or rented)	___
2. Intermediate forms of accommodation (not dementia-specific)	___
3. Dementia-specific residential accommodation	___
4. Long-term institutional care	___
5. Other ______________________________	___

A2.2 Patient Health Care Resource Utilization

1. During the last 30 days, how many times was the patient admitted in a hospital (for more than 24 hours)?

|__|__| Number of times ☐ None

2. If the patient was admitted in a hospital during the last 30 days, please specify the total number of nights spent in each type of ward.

Ward	Number of nights during the last 30 days
Geriatric	
Psychiatric	
Internal medicine	
Surgery	
Neurology	
General ward	
Other (please specify)	

3. During the last 30 days, how many times did the patient receive care in a hospital emergency room (for less than 24 hours)?

|__|__| Number of times ☐ None

Patient medication $

Other health problem: –

4. During the last 30 days, consider how many times the patient visited a doctor, physiotherapist, psychologist or other health care professional. Please specify the number of visits for each type of care received.

☐ The patient did not visit any of these health care professionals during the last 30 days

Type of care	Number of visits during last 30 days
General practitioner	
Geriatrician	
Neurologist	
Psychiatrist	
Physiotherapist	
Occupational therapist	
Social worker	
Psychologist	
Other (e.g. specialist; please specify)	

5. For each service listed below, please specify the number of times the service was received during the last 30 days and the average number of hours per visit.

☐ The patient did not receive any of these services during the last 30 days

Service	Number of visits during last 30 days	Number of hours per visit
District nurse		
Home aid/orderly		
Food delivery		N/A
Day care		
Transportation (care related)		N/A
Other (e.g. please specify)		

Barthel Index of Activities of Daily Living

Instructions: Choose the scoring point for the statement that most closely corresponds to the patient's current level of ability for each of the following 10 items. Record actual, not potential, functioning. Information can be obtained from the patient's self-report, from a separate party who is familiar with the patient's abilities (such as a relative), or from observation. Refer to the Guidelines section on the following page for detailed information on scoring and interpretation.

The Barthel Index

Bowels
0 = incontinent (or needs to be given enemata)
1 = occasional accident (once/week)
2 = continent
Patient's Score: ____________

Bladder
0 = incontinent, or catheterized and unable to manage
1 = occasional accident (max. once per 24 hours)
2 = continent (for over 7 days)
Patient's Score: ____________

Grooming
0 = needs help with personal care
1 = independent face/hair/teeth/shaving (implements provided)
Patient's Score: ____________

Toilet use
0 = dependent
1 = needs some help, but can do something alone
2 = independent (on and off, dressing, wiping)
Patient's Score: ____________

Feeding
0 = unable
1 = needs help cutting, spreading butter, etc.
2 = independent (food provided within reach)
Patient's Score: ____________

Transfer
0 = unable – no sitting balance
1 = major help (one or two people, physical), can sit
2 = minor help (verbal or physical)
3 = independent
Patient's Score: ____________

Mobility
0 = immobile
1 = wheelchair independent, including corners, etc.
2 = walks with help of one person (verbal or physical)
3 = independent (but may use any aid, e.g., stick)
Patient's Score: ____________

Dressing
0 = dependent
1 = needs help, but can do about half unaided
2 = independent (including buttons, zips, laces, etc.)
Patient's Score: ____________

Stairs
0 = unable
1 = needs help (verbal, physical, carrying aid)
2 = independent up and down
Patient's Score: ____________

Bathing
0 = dependent
1 = independent (or in shower)
Patient's Score: ____________

Total Score: ____________

(Collin et al., 1988)

Scoring:

Sum the patient's scores for each item. Total possible scores range from 0 – 20, with lower scores indicating increased disability. If used to measure improvement after rehabilitation, changes of more than two points in the total score reflect a probable genuine change, and change on one item from fully dependent to independent is also likely to be reliable.

Sources:

- Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. *Int Disabil Stud.* 1988;10(2):61-63.
- Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index. *Md State Med J.* 1965;14:61-65.
- Wade DT, Collin C. The Barthel ADL Index: a standard measure of physical disability? *Int Disabil Stud.* 1988;10(2):64-67.

Guidelines for the Barthel Index of Activities of Daily Living

General

- The Index should be used as a record of what a patient ***does***, NOT as a record of what a patient ***could do***.
- The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
- The need for supervision renders the patient not independent.
- A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives, and nurses will be the usual source, but direct observation and common sense are also important. However, direct testing is not needed.
- Usually the performance over the preceding 24 – 48 hours is important, but occasionally longer periods will be relevant.
- Unconscious patients should score '0' throughout, even if not yet incontinent.
- Middle categories imply that the patient supplies over 50% of the effort.
- Use of aids to be independent is allowed.

Bowels (preceding week)

- If needs enema from nurse, then 'incontinent.'
- 'Occasional' = once a week.

Bladder (preceding week)

- 'Occasional' = less than once a day.
- A catheterized patient who can completely manage the catheter alone is registered as 'continent.'

Grooming (preceding 24 – 48 hours)

- Refers to personal hygiene: doing teeth, fitting false teeth, doing hair, shaving, washing face. Implements can be provided by helper.

Toilet use

- Should be able to reach toilet/commode, undress sufficiently, clean self, dress, and leave.
- 'With help' = can wipe self and do some other of above.

Feeding

- Able to eat any normal food (not only soft food). Food cooked and served by others, but not cut up.
- 'Help' = food cut up, patient feeds self.

Transfer

- From bed to chair and back.
- 'Dependent' = NO sitting balance (unable to sit); two people to lift.
- 'Major help' = one strong/skilled, or two normal people. Can sit up.
- 'Minor help' = one person easily, OR needs any supervision for safety.

Mobility

- Refers to mobility about house or ward, indoors. May use aid. If in wheelchair, must negotiate corners/doors unaided.
- 'Help' = by one untrained person, including supervision/moral support.

Dressing

- Should be able to select and put on all clothes, which may be adapted.
- 'Half' = help with buttons, zips, etc. (*check!*), but can put on some garments alone.

Stairs

- Must carry any walking aid used to be independent.

Bathing

- Usually the most difficult activity.
- Must get in and out unsupervised, and wash self.
- Independent in shower = 'independent' if unsupervised/unaided.

(Collin et al., 1988)

Appendix 4 Chinese Mini Mental State Examination (CMMSE)[25]

Items	Score
What day of the week is it?	1
What is the date today?	1
What is the month?	1
What is the year?	1
Where are we now?	1
What floor are we now?	1
In which estate are we?	1
In which country are we?	1
Repeat the following words: "Lemon, Key, Balloon"	3
Substract $7 from $100 and make 5 subtractions	5
Can you recall the three wods	3
What is this? (show a pencil)	1
What is this? (show a watch)	1
Repeat the following:	
a) "No ifs, ands or buts" (English)	1
b) "Forty-four stone lions" (Chinese)	
Follow 1 3-stage command:	
"Take this piece of paper, fold it in half, and put it on the floor	3
Say a sentence of your choice	1
Read and obey what is written on this piece of paper	
"Raise your hands"	1
Copy this drawing on a piece of paper	1
Total score	

(Source: Sahadevan S et al, 2000)

Costs of Informal Care of Dementia in Singapore (RUD Study)

Data Collection Form for Patient Information

1. Age of Patient: ___________.
2. Gender of Patient: Male Female
3. Housing Type: ___________________________.
4. Diagnosis (type of dementia, if known): ___________________________.
5. Date of diagnosis (if known): . ________________.
6. Last known MMSE score ____/30.
7. Date of last MMSE . _________________.
   a. MoCA (if done) : Score = ________. Date done: _____________.
   b. CDR stage (if known): Score = ______. Date done: _____________.
8. Patient medications:

Name of medication	Strength (mg)	Number of times per day	Number of days taken in the last 30 days