UNIVERSITI PUTRA MALAYSIA

ECONOMIC BURDEN OF DEMENTIA AND HEALTHCARE COSTS OF DEMENTED ELDERLY IN MALAYSIA

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ECONOMIC BURDEN OF DEMENTIA AND HEALTHCARE COSTS OF DEMENTED ELDERLY IN MALAYSIA

By

ROSHANIM BINTI KORIS

Thesis Submitted to the School of Graduate Studies, Universiti Putra Malaysia, in Fulfillment of the Requirements for the Degree of Doctor of Philosophy

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DEDICATION

Kusyukuri nikmat hidup ini dan segalanya atas izin-Nya
Allah SWT Yang Maha Esa

Kehadiranmu melengkapkan hidupku dan menginspirasikanku
Nor Isman Bin Maserom
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"Terima Kasih"

"If we are destined for longevity, being old is a certainty, but being healthy in old age is an option. Therefore, practising a healthy lifestyle, eating healthy foods, using safe products and preserving the brain functions while young will keep us healthy in old age."
(Koris, 2018)

"No health without mental health"
(Prince, Patel, Saxena, Maj, Maselko, Phillips et al., 2007)

Abstract of thesis presented to the Senate of Universiti Putra Malaysia in fulfillment of the requirement for the degree of Doctor of Philosophy

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By

ROSHANIM BINTI KORIS

August 2018

Chairman: Associate Professor Norashidah binti Mohamed Nor, PhD
Faculty : Economics and Management

Worldwide, the ageing population is one of the phenomena that cannot be dismissed because of its great social, economic and cultural challenges to individuals, families and societies. The physical and mental health of the elderly should be society's main concern. The World Health Organisation (WHO) stated that 23% of chronic non-communicable diseases (NCD) are associated with older people. One of the leading contributors to mental and neurological disorders is dementia. The Alzheimer Disease Report stated that the global costs of treating dementia increased from USD604 billion in 2010 to USD818 billion in 2015, which represents 1.09% of global GDP. These costs are expected to reach USD1 trillion in 2018 and to double by 2030. Malaysia is no exception to this trend and is also experiencing the same phenomenon with the number of the elderly increasing and the prevalence of dementia is expected to rise. The specific objectives of this study are first, to estimate the direct and indirect costs incurred by the elderly with dementia both in the community and institutional settings in Malaysia; and secondly, to examine the economic burden of dementia both on individual and national income bases. The third objective is to investigate the determinants of the total healthcare costs for dementia patients. Using a multi-stage sampling design, this study investigated 2274 elderly from four states in Malaysia which have the highest number of adults aged 60 years and above, namely Johor (South Region), Kelantan (East Region), Perak (North Region) and Selangor (Central Region). The Mini-Mental State Examination (MMSE) score was used to measure the cognitive capability among the elderly. Only the elderly with a score of less than 19 marks were selected for further analysis. They were

organised into three categories: mild dementia, moderate dementia or severe dementia. The Cost of Illness (CoI) approach was used to analyse the direct and indirect costs from the community setting. The step-down approach made use of the Clinical Cost Modelling (CCM) Software version 3.0 to estimate the provider costs from an institutional setting. The results revealed that the prevalence of dementia is 17.8%. For each individual, the annual direct and indirect costs are RM12,613, RM14,635 and RM18,730 for mild, moderate and severe cases, respectively. The highest direct cost incurred by the demented elderly as outpatients according to the referred disease is cancer and as inpatients, it is vision problems. For the indirect costs, heart disease is the highest contributor to the cost regardless of whether the demented elderly are outpatients or inpatients. The highest direct cost and indirect cost according to the facilities referred to is when the demented elderly used private medical facilities as outpatients, and government facilities as inpatients respectively. This study also estimates that the total economic burden of dementia was around RM8 billion in 2014, and it represents 0.72% of the Malaysian GDP. In terms of the economic burden to the elderly individually, the study indicates that only 1.2% of the elderly with dementia bear the burden of huge expenditure whereby their out-of-pocket health expenditure exceeded 10% of the household income. Using a two-part model, it was found that household income and education level influence the healthcare cost with a positive relationship. However, age influences healthcare costs with a negative relationship. The number of diseases, the frequency of healthcare visits and admissions also affect healthcare cost. This shows that the demented elderly spend more money on healthcare facilities not because they are old, but because they are suffering from diseases. It is hoped that this study will rise up the issues of dementia as a priority in public health and social care in Malaysia. Appropriate actions to prevent dementia and other diseases are needed to ensure good physical and mental health of the elderly population. Financial assistance is essential to avoid the elderly from experiencing catastrophic health expenditure. The main impact of this study is the hope that the economic burden and the healthcare costs among the demented elderly in Malaysia could be minimised. Subsequently, the national vision to generate healthy, successful and productive ageing can be better achieved.

Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia sebagai memenuhi keperluan untuk ijazah Doktor Falsafah

BEBAN EKONOMI BAGI DEMENSIA DAN KOS PENJAGAAN KESIHATAN WARGA TUA YANG DEMENSIA DI MALAYSIA

Oleh

ROSHANIM BINTI KORIS

Ogos 2018

Pengerusi: Profesor Madya Norashidah binti Mohamed Nor, PhD
Fakulti : Ekonomi dan Pengurusan

Di peringkat global, penuaan penduduk adalah salah satu fenomena yang tidak dapat disangkal kerana ianya memberikan cabaran yang besar dari segi sosial, ekonomi dan budaya kepada individu, keluarga dan masyarakat. Kesihatan warga tua secara fizikal dan mental adalah isu utama yang harus dberi perhatian oleh semua pihak. Organisasi Kesihatan Dunia (WHO) melaporkan bahawa 23% penyakit tidak berjangkit (NCD) yang kronik berlaku di kalangan warga tua. Salah satu penyumbang utama adalah gangguan mental atau neurologikal seperti demensia. Laporan Penyakit Alzheimer menyatakan bahawa kos demensia global telah meningkat daripada USD604 bilion pada tahun 2010 kepada USD818 bilion pada tahun 2015, yang mana ianya mewakili 1.09% daripada KDNK global. Kos tersebut dianggarkan mencapai USD1 trilion pada tahun 2018 dan meningkat dua kali ganda pada tahun 2030. Malaysia tidak terkecuali dan juga sedang mengalami fenomena yang sama di mana bilangan orang tua semakin meningkat dan kelaziman demensia dijangka turut meningkat. Objektif khusus kajian ini adalah yang pertama, untuk menganggarkan kos langsung dan tidak langsung yang ditanggung oleh warga tua dengan demensia dalam persekitaran komuniti dan persekitaran institusional di Malaysia; dan kedua, untuk menilai beban ekonomi terhadap warga tua yang mengalami demensia secara individu dan pendapatan negara keseluruhannya. Objektif ketiga ialah untuk mengenal pasti penentu-penentu jumlah kos penjagaan kesihatan dalam kalangan warga tua yang mengalami demensia. Dengan menggunakan reka bentuk pensampelan pelbagai peringkat, kajian ini memilih 2274 orang tua dari empat negeri yang mempunyai bilangan warga tua tertinggi yang berumur 60 tahun ke atas iaitu Johor (Wilayah Selatan), Kelantan (Wilayah Timur), Perak (Wilayah Utara) dan Selangor (Wilayah Tengah). "Skor Peperiksaan Mini

Mental-Melayu" (MMSE-M) telah digunakan untuk mengukur keupayaan kognitif dalam kalangan warga tua ini. Hanya warga tua dengan skor kurang daripada 19 markah dipilih untuk analisis lanjut dan dikelaskan sama ada demensia ringan, demensia sederhana atau demensia yang teruk. Pendekatan "kos penyakit" (CoI) digunakan untuk menganalisis kos langsung dan tidak langsung dari persekitaran komuniti dan pendekatan step-down menggunakan perisian Clinical Cost Modelling (CCM) versi 3.0 untuk menganggarkan kos penyedia penjagaan kesihatan dari persekitaran institusional. Keputusan mendedahkan, kelaziman demensia adalah 17.8%. Bagi setiap individu, kos langsung dan tidak langsung tahunan adalah RM12,613, RM14,635 and RM18,730 untuk kes demensia ringan, demensia sederhana dan demensia teruk masing-masing. Kos langsung tertinggi yang ditanggung oleh warga tua demensia sebagai pesakit luar berdasarkan penyakit yang dirujuk, adalah kanser dan sebagai pesakit dalam, adalah masalah penglihatan. Bagi kos tidak langsung, penyakit jantung adalah penyumbang tertinggi kepada kos sama ada sebagai pesakit luar atau pesakit dalam. Kos langsung dan kos tidak langsung tertinggi berdasarkan fasiliti kesihatan yang dirujuk adalah apabila warga tua yang demensia menggunakan faciliti kesihatan swasta sebagai pesakit luar, dan fasiliti kesihatan kerajaan sebagai pesakit dalam masing-masing. Kajian ini juga menganggarkan beban ekonomi bagi demensia adalah kira-kira RM8 billion pada tahun 2014 dan ianya mewakili 0.72% daripada KDNK Malaysia secara keseluruhannya. Dari segi beban ekonomi kepada warga tua secara individu, penemuan ini menunjukkan hanya 1.2% orang tua yang demensia menanggung bencana perbelanjaan kesihatan di mana perbelanjaan kesihatan dari poket (OOP) mereka melebihi 10% daripada pendapatan isi rumah. Dengan menggunakan model dua-bahagian, pembolehubah utama iaitu pendapatan isi rumah dan tahap pendidikan mempengaruhi kos penjagaan kesihatan dengan hubungan positif dan umur mempengaruhi kos dengan hubungan yang negatif. Bilangan penyakit, bilangan lawatan dan kemasukan ke fasiliti kesihatan juga mempengaruhi kos penjagaan kesihatan. Ini menunjukkan warga tua yang demensia akan membelanjakan wang yang banyak terhadap fasiliti penjagaan kesihatan bukan kerana mereka tua, tetapi kerana mereka berpenyakit. Kajian ini diharapkan dapat menonjolkan isu-isu demensia sebagai satu keutamaan dalam kesihatan umum dan penjagaan sosial di Malaysia. Tindakan yang sesuai untuk mencegah penyakit demensia dan penyakit-penyakit lain adalah diperlukan untuk memastikan kesihatan fizikal dan mental yang baik bagi populasi tua. Bantuan kewangan juga penting untuk mengelakkan warga tua menanggung perbelanjaan kesihatan yang tinggi. Impak utama kajian ini adalah diharapkan beban ekonomi bagi demensia dan kos penjagaan kesihatan dalam kalangan warga tua yang demensia di Malaysia boleh diminimumkan. Sekaligus visi nasional untuk menghasilkan penuaan yang sihat, berjaya dan produktif akan lebih mudah tercapai.

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TABLE OF CONTENTS

		Page
ABSTRACT		i
ABSTRAK		iii
ACKNOWLEDGEMENTS		v
APPROVAL		vi
DECLARATION		viii
LIST OF TABLES		xiii
LIST OF FIGURES		xv
LIST OF ABBREVIATIONS		xvi
CHAPTER		
1	**BACKGROUND AND SIGNIFICANCE OF THE STUDY**	1
1.1	Introduction	1
1.2	Background of the Study	2
1.2.1	Population Ageing	2
1.2.2	Age-Related Disease	7
1.2.3	Economic Burden of Dementia and Healthcare Costs	8
1.3	Research Problem Statement	12
1.4	Research Objectives	14
1.5	Contribution and Significant of the Study	15
1.6	Limitations of the Study	16
1.7	Organisation of Chapters	17
2	**LITERATURE REVIEW**	18
2.1	Introduction	18
2.2	Theoretical Literature	18
2.2.1	The Third Generation of Social Gerontological Theories	19
2.2.2	The Theory of Health Demand	22
2.2.3	The Cost Analysis: Cost of Illness Approach	28
2.3	The Empirical Literature Review	30
2.3.1	Prevalence of Dementia in Malaysia	30
2.3.2	Cost of Illness: The Direct and Indirect Costs of Dementia	31
2.3.3	The Out-of-Pocket and Catastrophic Health Expenditure	34
2.3.4	The Determinants of the Total Cost of Dementia and Catastrophic Health Expenditure	36
2.4	Literature Gap	41
2.5	Chapter Summary	42

3 RESEARCH METHODOLOGY 43
3.1 Introduction 43
3.2 General Methodology for Setting and Study Design 43
3.2.1 Sampling Frame and Sample Size 44
3.2.2 Sampling Design 45
3.2.3 Sampling Criteria 46
3.2.4 Data Collection Procedure, Technics and Ethical Approval 46
3.2.5 Data Collection Tools 47
3.3 Methodology for Specific Objectives 49
3.3.1 Objective 1: Estimation of the Direct and Indirect Costs 49
3.3.2 Objective 2: Economic Burden to the Elderly with Dementia Individually and to the Nation 59
3.3.3 Objective 3: The Determinants of Total Cost Among the Elderly with Dementia 64
3.4 Protection of Human Subjects 68
3.5 Chapter Summary 68

4 FINDINGS AND DISCUSSION 69
4.1 Introduction 69
4.2 General Findings 69
4.2.1 Preliminary Analysis of the Socio-Demographic Characteristics, Economic Profile, Health Status and Hospital Utilisation for All Respondents 69
4.2.2 Preliminary Analysis of the Socio-Demographic Characteristics, the Economic Profile, Health Status and Hospital Utilisation for the Elderly with Dementia 76
4.2.3 Preliminary Analysis of the Direct and Indirect Costs of Healthcare Utilisation for All Elderly and the Elderly with Dementia 86
4.3 Findings by Specific Objectives 90
4.3.1 Objective 1 (i): The Direct and Indirect Costs Incurred by the Elderly with Dementia in the Community Setting 91
4.3.2 Objective 1 (ii): The Direct Cost Incurred by the Government Providers in Institutional Settings in Malaysia 103
4.3.3 Objective 2 (i): The Economic Burden on the Elderly with Dementia 104
4.3.4 Objective 2 (ii): Economic Burden of Dementia on the National Income 109
4.3.5 Objective 3: The Determinants of Total Healthcare Cost of the Demented Elderly 112

4.4 Chapter Summary 117

5 CONCLUSION AND POLICY IMPLICATIONS 118
5.1 Introduction 118
5.2 Summary and Conclusion 118
5.3 Policy Implications and Recommendations 121
5.4 Future Research 123
5.5 Chapter Summary 123

REFERENCES 125
APPENDICES 144
BIODATA OF STUDENT 183
LIST OF PUBLICATIONS 184

LIST OF TABLES

Table		Page
1.1	Indicators of the Demographic Determinants of Population Ageing, Malaysia, 1950-2050	5
1.2	Percentage in Older Age, Median Age and Dependency Ratio, Malaysia, 1950-2050	6
3.1	The Classifications of Direct Costs and Indirect Costs in the Community Setting	52
3.2	Categories for Type of Facilities and Diseases Referred	55
3.3	Classification of Cost Center in Costing Template	56
3.4	Unit Costs Outpatient and Inpatient with Dementia by Government Providers in Institutional Setting	58
3.5	Percentage of Household Consumption Expenditure by Strata, Malaysia, 2014	61
3.6	Notation and Description Variables	67
4.1	Descriptive Analysis of the Socio-Demographic Characteristics for All Respondents	71
4.2	Descriptive Analysis of the Economic Profile for All Respondents	72
4.3	Health Status and Diseases Diagnosed for All Respondents	73
4.4	Healthcare Utilisation by Diseases Referred for All Elderly	75
4.5	Healthcare Utilisation by Facilities Referred for All Elderly	76
4.6	Descriptive Analysis of the Socio-Demographic Characteristics for the Elderly with Dementia	77
4.7	Descriptive Analysis of the Economic Profile for the Elderly with Dementia	81
4.8	Health Status and Diseases Diagnosed for All Respondents	83
4.9	Outpatient Care, Inpatient Care and Diseases Referred by Severity of Dementia	84

4.10 Outpatient Care, Inpatient Care and Facilities Referred by the Severity of Dementia 85

4.11 The Direct and Indirect Costs by Socio-Demographic Profile for All Elderly with Dementia 94

4.12 The Direct and Indirect Costs by Socio-Demographic Profile for the Elderly with Mild Dementia 95

4.13 The Direct and Indirect Costs by Socio-Demographic Profile for the Elderly with Moderate Dementia 96

4.14 The Direct and Indirect Costs by Socio-Demographic Profile for the Elderly with Severe Dementia 97

4.15 The Direct and Indirect Costs of Diseases Referred to Outpatient Care 98

4.16 The Direct and Indirect Costs of Diseases Referred to Inpatient Care 100

4.17 The Direct and Indirect Costs by Facilities Referred as Outpatient Care 102

4.18 The Direct and Indirect Costs by Facilities Referred as Inpatient Care 103

4.19 Direct Cost of Treating Dementia in Outpatient and Inpatient Care for Government Providers 104

4.20 Prevalence of Catastrophic Health Expenditure among the Elderly with Dementia 105

4.21 Incidence of Catastrophic Health Expenditure among the Elderly by Cognitive Status 105

4.22 Number and Percentage of the Elderly with Catastrophic Health Expenditure by Severity Level for Selected Variables 107

4.23 Economic Burden of Dementia on the Malaysian National Income, 2014 110

4.24 The Two Part Model Predicting the Determinants of Total Healthcare Cost among the Elderly with Dementia 113

LIST OF FIGURES

Figure		Page
1.1	Trends of Elderly People Globally, 1980-2050	4
1.2	Trends of Elderly People in Malaysia, 1960-2020 ('000)	4
2.1	Determinations Optimal Health Stock	23
2.2	Production Function of Healthy Days	24
2.3	The Changes in Optimal Health Stock	25
2.4	The Grossman Model for Health Demand and Demand for Health Services	27
3.1	Conceptual Framework of Quantifying Direct Costs, Indirect Costs and Data Merging	50
3.2	Theoretical Framework of the Determinants of the Total Cost of Health Expenditure	66
4.1	Mean Annual Total Cost of Outpatient and Inpatient Care among All Elderly	87
4.2	Mean Annual Direct and Indirect Costs of Outpatient Care and Inpatient Care among All Elderly	87
4.3	Mean Annual Total Cost of Outpatient and Inpatient Care among the Elderly with Dementia	88
4.4	Mean Annual Direct and Indirect Costs of Outpatient Care among the Elderly with Dementia	88
4.5	Mean Annual Direct and Indirect Costs of Inpatient Care among the Elderly with Dementia	89

LIST OF ABBREVIATIONS

AD	Alzheimer's disease
ADL	Activities Of Daily Living
ARD	Age-related disease
CCM	Clinical Cost Modeling Software Version 3.0
CHE	Catastrophic health expenditure
CoI	Cost of illness
CPG	Clinical Practice Guidelines
DLB	Dementia with Lewy bodies
DMC	Total Direct Medical Cost
DNMC	The Total Direct Non-Medical Cost
DOSM	Department of Statistic Malaysia
EGD	Expert Group Discussion
FTD	Frontotemporal Dementia
GDP	Gross Domestic Product
GMS	Geriatric Mental State
IADL	Instrumental ADL
IDC	The Total Indirect Cost
LOS	Length Of Stay
MCI	Mild Cognitive Impairment
MMSE	Mini-Mental State Examination
MoCA	Montreal Cognitive Assessment
MOH	Ministry of Health
NCD	Non-communicable diseases

NHMS	National Health Malaysian Survey
NKRA	National Key Results Areas
OOP	Out-of-pocket
PD	Parkinson's disease
UKMMC	Universiti Kebangsaan Malaysia Medical Clinic
UN	United Nation
VaD	Vascular dementia
WHO	World Health Organization

CHAPTER 1

BACKGROUND AND SIGNIFICANCE OF THE STUDY

1.1 Introduction

One of the main issues that have attracted the attention of many researchers and policymakers worldwide recently is the issue of an ageing population. The number of older aged people is forecasted to increase dramatically in the next 40 years. The process of human ageing will affect the deterioration of human body strength both physically and mentally. In addition, the ageing process also causes the human brain to shrink and causes the cognitive functions to be impaired (Farooqui & Farooqui, 2009).

According to Scott and Barrett (2007), over 40 years ago, formal studies of cognitive impairment such as memory function and ageing were done to prove the existence of age-related memory decline. Meanwhile, Birren, Butler, Greenhouse, Sokoloff, and Yarrow (1963) stated that memory decline was generally associated with ageing and even the healthiest older men also faced the problem. One of the most common diseases that are related to cognitive impairment is dementia. Besides that, people with memory impairment who were not demented were characterised as having mild cognitive impairment (MCI henceforth) and at an increased risk of developing dementia. MCI is considered to be in between normal ageing and dementia.

Dementia is serious damage to the brain caused by various diseases and will destroy mental ability. It is also described as a group of symptoms affecting memory, behaviour, thinking and social abilities severely enough to disturb a person's daily functioning. Most older people have problems regarding short-term memory, which is a part of normal ageing or so-called age-related cognitive decline. However, dementia is not a normal part of ageing. There are at least two types of the following listed symptoms that are significant enough to interfere with everyday life to be considered a dementia diagnosis, aside from the difficulty in remembering, such as impairments in language, communication, focussing or reasoning. The subtypes of dementia disease are Alzheimer's disease (AD), vascular dementia (VaD), frontotemporal dementia (FTD), dementia with Lewy bodies (DLB), mixed dementia, Parkinson's disease (PD), Creutzfeldt-Jakob disease and normal pressure hydrocephalus. Therefore, dementia and MCI diseases, if not curbed, will affect someone's quality of life and possibly cause them to need special care or to live dependently which is expected to have an impact on the rising cost of

healthcare (Salthouse, 2004). However, this study will discuss only the economic burden of dementia among the elderly in Malaysia.

Further, this chapter will begin with the background of this study which explains how the phenomenon of population ageing has been happening worldwide, specifically in Malaysia and the description of age-related diseases i.e. dementia emanating from an increasingly elderly population. In the problem statement part, there is also a discussion about the cost of dementia and healthcare costs increasing continuously due to NCDs that are incurred by the elderly and society. Then, the research objectives and the contribution and significance of the study will be presented. The organisation of the chapters is shown at the end of this chapter.

1.2 Background of the Study

1.2.1 Population Ageing

In demographic terms, the causes of population ageing are divided into three concepts namely a reduction in fertility and a decline in mortality that leads to the third concept which is life expectancy or longevity increases (Martin & Dirk, 2012). It also shows that improvements in the healthcare system have yielded that many people are now living healthier and longer (Cutler, Deaton & Lleras-Muney, 2006). Meanwhile, the United Nations (UN) (2002) also examined the worldwide decline in fertility and mortality as the demographic determinants of population ageing. In Malaysia, older people are defined as those who are 60 years old and above a definition which had been adopted by consensus with the United Nations during the World Assembly on Ageing, 1982, held in Vienna, Austria. The population of Malaysia is still relatively young compared to those in other developed countries, but changes in the age structure resulting from a fertility decline and increased longevity are contributing to a population that is ageing.

There are three indicators that act as a cut-off to indicate and categorise a country as ageing, namely (i) more than 15 percent of the older people are aged 60 years old and above; (ii) a median age of 30 years; and (iii) an increasing of the old age dependency ratio (the ratio of the old population (60 years old and above) to the working-age population (15-59 years old)). According to Holzmann (2013), all countries in the world are ageing by at least one measure. Low and middle-income countries are projected to be ageing faster than higher-income countries. In addition, most low-income countries and many middle-income countries are becoming demographically old, before becoming economically rich.

According to the United Nation Report (2002), fertility in less developed regions, as a whole, is expected to drop from 2.73 children per woman in 2005-2010 to 2.05 children per woman in 2045-2050. The reduction projected for the group of the 49 least developed countries is even steeper, from 4.39 children per woman to 2.41 children per woman. In addition, over the last five decades, life expectancy at birth has increased globally by almost 20 years, from 46.5 years in 1950-1955 to 66.0 years in 2000-2005. Furthermore, over the next 50 years, life expectancy at birth is projected to increase globally by 10 years, to reach 76 years in 2045-2050. Besides that, under current mortality conditions, almost 3 out of every 4 new-borns in the world will survive to age 60, and about 1 out of every 3 new-borns will survive to age 80. Under the mortality conditions projected for the period 2045-2050, approximately 7 out of every 8 new-borns will survive to age 60, and more than half to age 80.

Therefore, with all of the indicators of the demographic determinants of population ageing, the United Nations (2009) reported that one in nine people in the world is aged 60 years old and over, and this is projected to increase to one in five by 2050. In other words, around the world, two people celebrate their sixtieth birthday every second or almost 58 million celebrate their sixtieth birthdays annually. In addition, the latest facts from the United Nations in their 2015 Revision of World Population Prospect reported that globally, the number of elderly aged 60 years old and above is expected to more than double by 2050 and more than triple by 2100. Meanwhile, in Asia, currently, the percentage of the elderly aged 60 years old and above is between 11% to 12% and this will increase by more than double to 25% by 2050.

Figure 1.1 shows that the proportion of older aged people has increased steadily by age group. It shows that by 2030, our world will become an old world because by then 16.5 percent of its citizens will be 60 years old and above. Followed by 11.7 percent who are older than 65 years and 2.4 percent who are 80 years old and above. If we take into account that one of the determinants of an ageing population is that 15 percent are above 60 years old, truly our world will be ageing before the year 2030. The numbers of the elderly are projected to increase continuously through to the year 2050 with 21.5 percent of the population projected to be 60 years old and above by then.

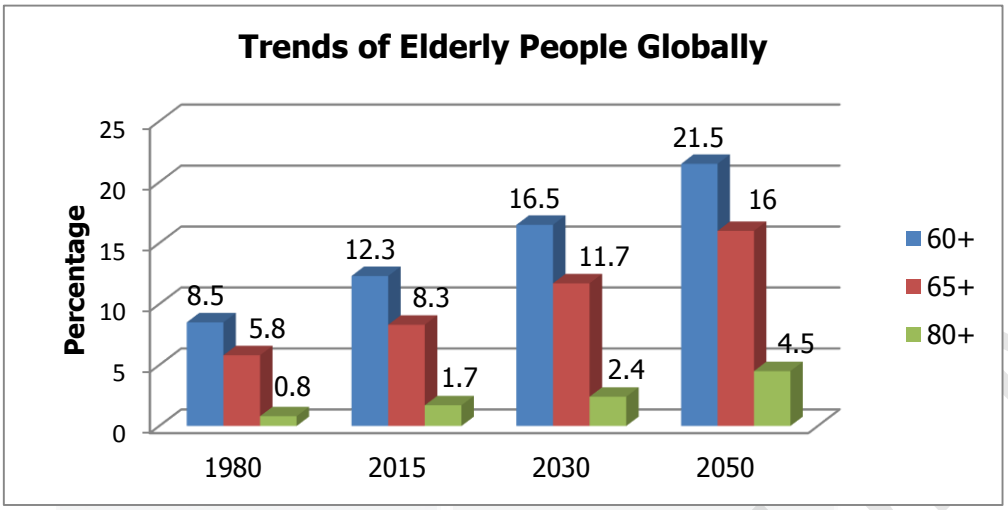

Figure 1.1 : Trends of Elderly People Globally, 1980-2050
(Source : United Nations Department of Economic and Social Affairs, Population Division 2002)

Meanwhile, Malaysia as a fast-developing country has shown an increment in the trend of population ageing over the last few decades. As shown in Figure 1.2, for the year 1970, the population aged 60 years old and above was about 546,000 people. Since then, the number has doubled, within 20 years, to 1.03 million people in 1991. The Census of Malaysia (2000) reported that 6.3 percent or 1.3 million people were 60 years old and above in the year 2000 and this was projected to reach 9.9 percent or 3.4 million people in 2020. In addition, the UN reported that the projected percentage of older aged people in Malaysia in 2025 and 2050 will increase to 13.4 percent and 20.8 percent respectively.

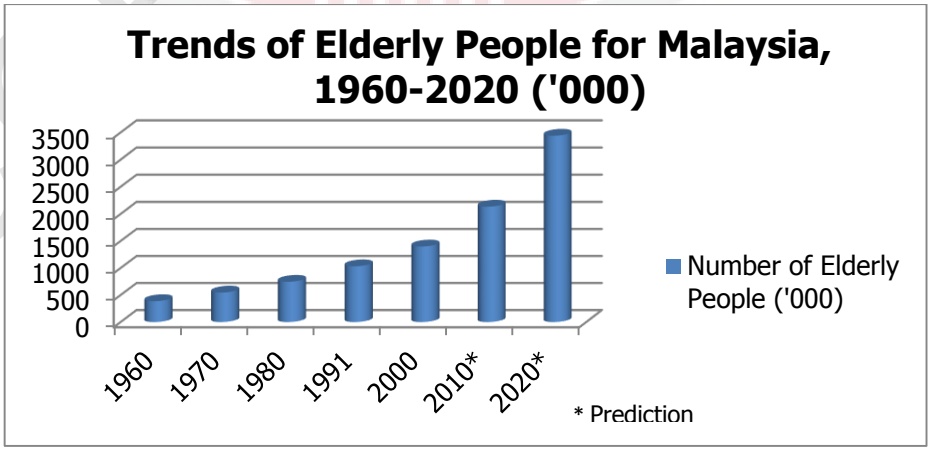

Figure 1.2 : Trends of Elderly People in Malaysia, 1960-2020 ('000)
(Source : Population and Housing Census of Malaysia, 2000, DOS)

The trend of population ageing in Malaysia stems from the three indicators of the demographic determinants of population ageing that were discussed above. According to Table 1.1, the number of elderly, aged 60 years old and above, in Malaysia is expected to increase by 2025-2030 by as much as three percent and a further two percent by 2045-2050. The same pattern is followed by the elderly aged 65 and above and 80 and above. As for the fertility rate, this has dropped from 6.8 children per woman in 1950-1955 to 2.9 children per woman in 2000-2005. This number is expected to drop further to 2.1 children per woman in 2025-2030 and 2045-2050. Improvements in healthcare and lifestyle have led to a decrease in the mortality rate and increased life expectancy among the elderly between 60 to 80 years old and this is expected to increase by between 8 to 20 years more by 2045-2050. Meanwhile, the survival rate for Malaysian elderly to reach age 60 and 65 years is projected to increase to 85.4 percent and to 92.9 percent by 2025-2030 and 2045-2050 respectively. For the survival rate until age 80, Malaysian elderly are forecasted with a 49.0 percent chance to reach this by 2025-2030 and increasing to a 56.5 percent chance by 2045-2050, compared to a 36.5 percent chance for 2000-2005.

Table 1.1 : Indicators of the Demographic Determinants of Population Ageing, Malaysia, 1950-2050

Indicator	1950 - 1955	1975 - 1980	2000 - 2005	2025 - 2030	2045 - 2050
Growth rate (%) Total	2.7	2.3	1.7	1.0	0.5
Growth rate (%) 60+	-1.4	2.7	3.3	3.0	2.0
Growth rate (%) 65+	-0.7	1.9	4.3	3.9	2.6
Growth rate (%) 80+	0.6	2.3	2.2	6.2	2.8
Total fertility rate (per woman)	6.8	4.2	2.9	2.1	2.1
Life expectancy (years)	48.5	65.3	73.0	77.4	79.7
Birth					
60	--	--	18.1	20.6	22.4
65	--	--	14.5	16.8	18.4
80	--	--	6.7	7.8	8.9
Survival Rate (%)					
To 60 years	--	--	85.4	91.1	92.9
To 65 years	--	--	78.0	85.7	88.5
To 80 years	--	--	36.5	49.0	56.5

(Source : United Nations, Department of Economic and Social Affairs, Population Division 2002)

Therefore, fertility, life expectancy and mortality (shown by the survival rate) are closely related concepts that represent the factors of an ageing population. Many researchers agree that changes in these three concepts will cause changes in the population structure as suggested by Balkenende (2008); V. Ewijk and T. Rele (1999); Harper (2006); Tsuno and Homma (2009); Hashimoto and Tabata (2010); Frank et al. (2005) and Ludwig and Vogel (2010). Specifically, the decline in fertility and mortality, as well as the increase in life expectancy and the survival rate, will cause the population ageing phenomenon. These demographic changes are also known as demographic transitions.

Despite Malaysia being considered as a young country where the total of elderly people for the year 2020 is projected to be only 9.9 percent of the total population, it has experienced the 'phenomenon of population ageing' because the percentage is greater than 7 percent (UN, 2002). Moreover, the trends of all indicators are in line with an age structure transition towards an ageing population in Malaysia, this is shown in Table 1.2. The median age of the Malaysian population increased from 17.4 years in 1970 to 23.6 years in 2000 and in the year 2020, it is projected to rise to 27.1 years, 31.2 years by 2025 and 37.8 years by 2050. Meanwhile, the old age dependency ratio is expected to increase to 13.4 by 2025 as compared to 6.7 in 2000. The forecasted ratio for 2050 is nearly double at 23.8.

Kinsella and He (2009) found that Malaysia will be the fourth fastest ageing nation with an increase of 269 percent between 2008 to 2040 just behind Singapore, Colombia and India. Hence, Malaysia is forecasted to become an ageing country in 2030 with 15 percent of the population elderly. This is consistent with the projection that the world will also be ageing as a whole by 2030 when 1.3 billion people or 15 percent of the world's population are 'greying' people (DOS, 2005).

Table 1.2 : Percentage in Older Age, Median Age and Dependency Ratio, Malaysia, 1950-2050

Ratios	1950	1975	2000	2025	2050
Older Ages (%) at 60+	7.3	5.6	6.6	13.4	20.8
Older Ages (%) at 65+	5.1	3.7	4.1	9.0	15.4
Older Ages (%) at 80+	0.6	0.5	0.6	1.3	3.7
Median Age (years)	19.8	18.6	23.3	31.2	37.8
Total Dependency Ratio	85.0	84.6	61.9	48.4	54.4
Youth Dependency Ratio	75.7	77.7	55.2	35.0	30.6
Old Age Dependency Ratio	9.4	6.9	6.7	13.4	23.8

(Source : United Nations, Department of Economic and Social Affairs, Population Division 2002)

1.2.2 Age-Related Disease

An ageing population has wide-ranging implications for virtually every aspect of Malaysian society. Thus, population ageing is one phenomenon that cannot be dismissed because of the great challenges socially, economically and culturally to individuals, families and society. Consequently, the main issue that society should be concerned about is the health of older people both physically and mentally. Hence, a key component of healthcare, associated with ageing, is the major age-related diseases (ARD henceforth) that influence the cost of healthcare for the elderly which increases and becomes a burden to individuals, families and society.

Moreover, the rise of chronic non-communicable diseases (NCD henceforth) reflects changes in lifestyle and diet, as well as ageing. NCDs also known as chronic diseases are generated from a combination of genetic, physiological, environmental and behavioural factors that will make people suffer over a long period (WHO, 2017). NCDs also affect economic and societal costs aggressively with age and have the potential to influence economic growth. As a result, the absolute number of years lived with disability from non-communicable diseases has been rising all over the world, not only because of population growth but also because of the ageing of populations (Global Burden of Disease, 2016).

Moreover, according to Prince, Wu, Guo, Robledo, O'Donnell et al. (2015) and Bloom, Cafiero, Jané-Llopis, Abrahams-Gessel et al. (2011), about 23% of the global burdens of diseases among older people are chronic NCDs with one of the leading contributors being mental and neurological disorders. Overall, the global cost of mental health illness including Alzheimer's disease and other dementias in 2010 was estimated at USD2.5 trillion and is projected to increase to USD6.0 trillion by 2030. About two-thirds of this total cost comes from indirect costs and the rest from direct costs (Bloom et al., 2011).

Since the late 1990s, the Ministry of Health, Malaysia (MOH) has emphasised mental health as a critical component of health and has integrated mental health services into primary healthcare services in public health clinics. The services include wellness promotion, prevention of mental disorders, mental health screening, treatment and the rehabilitation of patients affected by mental disorders. Promotional activities were undertaken as part of the Healthy Lifestyle Campaign. In 2012, a total of 144,476 elderly people were screened for the risk of mental health problems using the Screening Health Status Form and 0.4% was detected with mental health problems. By December 2012, a total of 1,302,422 elderly had been registered at public health clinics all over Malaysia which was only 55.7% of the elderly population.

There were 3.48 million elderly who attended public health clinics for new and repeat cases reported in the year 2012, compared to 1.14 million in the year 2010 and 1.18 million in 2008 (MOH, 2012). Besides that, various efforts have been undertaken by the government to ensure that all people of all ages have a healthy life. For example, The National Blue Ocean Strategy (NBOS) 7 – "1Malaysia Family Care" is an initiative by the government to provide holistic support for the elderly, people with disabilities and single mothers specifically.

Consequently, more elderly have utilised healthcare services to get treatment for their illnesses. The five most common morbidities among the elderly seen in public health clinics, which has followed the same pattern for the past five years, were hypertension, diabetes mellitus, joint, eye and respiratory problems. And additionally, dementia was listed in the top 10 new main diagnoses among the elderly who came to public healthcare facilities in 2012 (MOH, 2012).

Undeniably, elderly people are the most knowledgeable people in society with all of the experiences that they have gained throughout their lifetimes. However, they face difficulties in learning new things and memory loss if they have brain health problems and cognitive impairment. Furthermore, the situation could be exacerbated if they also suffer from other illnesses. They will consume a greater volume of healthcare facilities than those who are younger not because they are older, but because they are sick. Thus, they would spend more money on healthcare services to get better treatment for their illnesses (Cutler, 2001; Moïse and Jacobzone, 2003). It is even worse if the elderly with dementia have other illnesses or comorbidities. The elderly with cognitive impairment and comorbidity will need more special attention, assistance and facilities from others especially families and society. Again, this major ARD i.e. dementia will cause a significant impact in terms of healthcare costs to the patients, their families and society.

1.2.3 Economic Burden of Dementia and Healthcare Costs

Globally, the costs of dementia have increased from USD604 billion in 2010 to USD818 billion in 2015, an increase of 35.4% (The Alzheimer Disease Report, 2015). The estimation of USD818 billion represents 1.09% of the global GDP, an increase from 2010 which estimated only 1.01%. Excluding informal care costs, total direct costs accounted for 0.65% of global GDP. The distribution of costs between the three major subcategories (direct medical, social care, and informal care) has not changed substantially. Direct medical care costs are modest, accounting for roughly 20% of global dementia costs, while direct social sector costs and informal care costs are roughly 40% each respectively. The costs are also estimated to increase and to reach USD1 trillion in 2018

and to double by 2030. The report also described that if the economic cost of dementia were a country, it would be the world's 18th largest economy and higher than the market value of companies such as Apple and Google.

With the prevalence of dementia increasing dramatically, the healthcare costs of dementia and its subtypes such as Alzheimer's disease (AD) would soon surpass almost all other medical expenses. According to World Alzheimer Report (2015), approximately 46.8 million people worldwide were living with dementia in 2015 and this is estimated to nearly double every 20 years to make the figure rise to 74.7 million in 2030 and 131.5 million in 2050. These new estimations are different, about 12 to 13 percent higher than the estimations in the World Alzheimer Report 2009, because of new findings in the systematic review of the global prevalence of dementia. Meanwhile, the regional estimates for the prevalence of dementia among people aged 60 years old and above, ranges from 4.6 percent in Central Europe to 8.7 percent in North Africa and the Middle East. For other regions, the prevalence is in the range of 5.6 percent to 7.6 percent including Asia (World Alzheimer Report, 2015).

Consequently, the economic burden will escalate proportionately with the estimated prevalence due to increased demand for healthcare services, particularly in low and middle-income countries (WHO, 2012). (Wimo, Gustavsson, Jönsson, Winblad, Hsu & Gannon (2013) reported that the cost of dementia had already been contemplated many years ago in some regions and countries especially high-income countries such as the United States, the United Kingdom, Sweden, Australia and Canada. The evidence shows that the cost of dementia was already enormous and has been imposing a huge societal economic burden, through direct costs (medical and social care) and indirect costs (unpaid caregiving by families and friends). For instance, Hay et al., (1987); Østbye et al., (1994); Weinberger et al., (1993); Hux et al., (1998); Langa, Chernew, Kabeto et al. (2001); Érsek et al., (2010); Jonsson et al., (2006); Wimo et al., (2011) agreed that direct costs and indirect costs are the two cost components in their studies reach to million dollars up to a billion dollars annually. The indirect costs share the highest proportion about 90 percent of the total cost of dementia (Kraft et al., 2010).

All of the evidence that has been discussed above is from global data. With the same trends ageing the population globally, Malaysia is no exception as it has experienced an increasing prevalence of dementia and its associated costs. Wimo et al. (2007, 2010) estimated that the total cost of dementia for Malaysia was USD511 million with the total number of demented people being 62,177 in 2005. An Increase of 18 percent by 2009 brought the total number of demented people to 73,423. Meanwhile, the cost of dementia rose by 32

percent to make the total cost of dementia in 2009 to be USD672 million. The estimation used meta-analysis from previously published prevalence studies in Malaysia and the prevalence figures were updated in 2005 and 2009 and the costs were inflated in 2005 and 2009 respectively by country-specific data on the consumer price index (CPI).

Nevertheless, Hamid, M. Nor, Momtaz & Akhbar (2012-unpublished), attempted to estimate the cost of dementia in Malaysia by using the prevalence of dementia at the 14.3 percent level that was found in a previous nationwide study by Hamid, Krishnaswamy, Abdullah, & Momtaz (2010). They projected the number of older people with dementia by using the number of older people in the 2010 Census. Then, the cost of dementia was calculated using the prediction of the future cost of care by Wimo et al. (2007) which estimated that the unit cost for mild, moderate and severe dementia in Malaysia was USD8,219, USD12,596 and USD20,308 respectively. They found that the crude estimated cost of mild dementia in 2010 was USD2,011 million for 244,650 people, USD1,010 million for 80,212 people with moderate dementia, and USD145 million for 7,159 people with severe dementia. Meanwhile, the total direct costs and indirect costs were USD1,292 million and USD1,876 million respectively. This finding is alarming and will affect total health expenditure and thus, will impact the Malaysian GDP as a whole. Therefore, this study will provide new data on the prevalence of dementia and its costs by using real data from four main regions in Malaysia to represent the older people in Malaysia.

Meanwhile, when looking at the total expenditure on healthcare by public and private sectors, the numbers are in an increasing trend. Between 2004 to 2014, the total health expenditure for Malaysia ranged from RM19,037 million in 2004 to RM49,731 million in 2014. This shows that the costs have incremented by more than 160 percent in a decade. Health expenditure as a percentage of the Gross Domestic Product (GDP henceforth) also increased from 4.02 percent in 2002 to 4.49 in 2014. Meanwhile, the health expenditure per capita was RM990 (USD261) in 2004 and increased by about 64% in 2014 where the health expenditure per capita was RM1,625 (USD496).

The highest contributors to total health expenditure are come from expenditure by the Ministry of Health (MOH) in the range 43 to 46 percent between the years 2004 to 2014. It was followed by private household out-of-pocket health expenditure (OOP) in the range of 33 to 39 percent over the same period of time. Specifically, for the total OOP health expenditure among the elderly, The National and Morbidity Survey 2015 estimated that about 0.7 million elderly people spent about RM909 million in 2015 which was 7.8

percent of the overall total OOP health expenditure. There was a total of about RM476 million for OOP inpatient care and RM377 million for outpatient care.

According to the World Bank, OOP expenditure is any direct expense incurred by households, including payments to health practitioners and suppliers of pharmaceuticals, therapeutic appliances, and other goods and services whose main purpose is restorative or enhancement treatment of the health status of individuals or population groups, and it is a part of private health expenditure. In addition, the WHO defined OOP as direct payments made by individuals to healthcare facilities, but excludes any prepayment for health services, such as insurance premiums or contributions and any reimbursements to the individual who made the payments.

Household OOP health expenditure is the largest component of private health expenditure and the second largest contributor to total health expenditure in Malaysia. The impact of OOP payments for healthcare can become catastrophic over time and can significantly affect the living standards of individuals; this is called catastrophic health expenditure (CHE, henceforth). Especially for the poor and the elderly, the burdens of OOP payments are an inequitable way to finance a health system because the loads for various social groups are different (WHO, 2000). Meanwhile, Elgazzara et al. (2010) outlined three reasons why the burden of OOP payments should be the main agenda in health policy formulation: First, households may be pushed into poverty or hardcore poverty as a result of paying directly for health services. Second, households facing these health expenses may cut back on other basic and vital household expenditure such as food and clothing or even education. Third, households may choose to sacrifice necessary healthcare services rather than face financial insufficiency, thus, the consequences of this will create a vicious cycle of ill health, disability, and poverty.

In the absence of sufficient income and possibly with some of them living alone, the elderly are vulnerable to CHE, particularly the poorer elderly. In China, the elderly were noted to be more sensitive to CHE, especially those with two or more chronic diseases (Wang, Li & Chen, 2015). Health expenditures are considered to be catastrophic when the household spend on healthcare is more than some pre-specified threshold budget share (let's say z). Therefore, spending on healthcare equal or more than z is labelled as "catastrophic". In addition, CHE represents a household's financial capacity in an imperilled situation when the health expenditure is greater than the expenses for its subsistence needs (Kimani, Mugo & Kioko, 2016).

OOP expenditure for healthcare utilisation is frequently discussed at national and international levels. This shows that OOP is a major component of

healthcare and should be emphasised by the authorities, especially amongst stakeholders and policymakers. This is because a high level of OOP can give a negative impact on the economic status of individuals, households and the nation as a whole. There is enough evidence to show that high OOP spending can result in a catastrophic financial burden for individuals or households bringing on poverty. Even when the OOP expenditures on health are relatively small, the poor become poorer and when there is high health expenditure, the rich can become poor or even bankrupt because of financial catastrophe. This situation will finally lead to the poor economic status of a nation (Wagstaff & Doorslaer, 2003; OECD, 2011; Tomini, Packard & Tomini, 2012; Kimani et al., 2016).

1.3 Research Problem Statement

The first and foremost issue for this study is the economic burden of dementia and the burden of healthcare costs among the elderly with dementia in Malaysia as noted in the Background of the Study. The analysis of the economic burden of disease is important as guidance in making policy decisions that are significant to a particular disease such as dementia. Generally, the economic burden analysis can be discussed in terms of the microeconomic level such as households, firms or the government which is looking at the impact of the disease on human health, life, income, profit and welfare borne by the unit of economy respectively. On the other hand, in terms of the macroeconomic level, the analysis will provide the aggregate impact of a particular disease on a country's income specifically the current and future gross domestic product (GDP henceforth) (WHO,2009). The most common approach to estimate the economic burden of disease is called cost of illness (CoI henceforth). The CoI approach is the estimation of direct cost (medical and non-medical) and indirect cost (productivity loss) due to disease or injury which will give some impact on health outcomes in a country, institutional, communities, and also individuals (WHO, 2009; Jo, 2014).

Therefore, this study will discuss the economic burden in two ways. Firstly, at the microeconomic level where the burden of healthcare costs incurred by the individual elderly with dementia in terms of out-of-pocket (OOP henceforth) health expenditure and catastrophic health expenditure will be determined. Secondly, at the macroeconomic level where the economic burden of dementia is estimated by the overall cost which contains the provider costs that come from the institutional setting and private costs (patients' costs) that come from the community setting. The burden is shown in percentage terms as a share of the Gross Domestic Product (GDP henceforth). Thus, to realise the analysis of the economic burden on dementia and the burden on healthcare costs by the elderly with dementia, the first and most important steps are to estimate the direct and indirect costs for healthcare utilisation among the elderly with

dementia in both the community and institutional settings by using the CoI approach.

Consequently, the second issue highlighted in this study regards the elderly who have other comorbidities such as NCD. The most common NCDs are cardiovascular diseases such as heart disease and stroke, diabetes, hypertension, cancer, hypercholesterolemia and chronic respiratory diseases like asthma. The NHMS (National Health Malaysian Survey) 2015 reported that the prevalence of NCDs showed an increasing trend and contributed to an estimated 73% of the total deaths in Malaysia for the year 2015. The prevalence of three major NCD risk factors are high blood sugar (diabetes) and high blood cholesterol (hypercholesterolemia) continue to increase in Malaysia with 17.5% and 47.7% respectively in 2015 compared to 15.2% and 32.6% in 2011. Meanwhile, high blood pressure (hypertension) showed a decreased prevalence of 30.3% in 2015 compared to 2011 with 32.7%. However, the prevalence of these three NCDs is the highest among the elderly 60 years old and above with 38% for diabetes and 65% for hypertension and hypercholesterolemia. These NCDs are the highest contributors to the probability of developing dementia among the elderly. As proven in prior literature, diabetes mellitus and cardiovascular diseases increase the risk of dementia especially vascular dementia and Alzheimer's disease (Biessels et al., 2006; Peila et al., 2002; Fan et al., 2017). In addition, the risk of dementia and vascular dementia is particularly high when diabetes mellitus occurs together with severe hypertension or heart disease in older people (Xu, Qiu, Wahlin, Winblad, & Fratiglioni, (2004); Strachan et al., 2011; Sharp, Aarsland, Day et al., 2011). However, with the well-managed control of comorbidities the progression and severity of dementia could be reduced (Azhar, Pangle and Wei, 2017). Some studies have agreed that the elderly with dementia who have NCDs tend to utilise more healthcare facilities and bear higher healthcare expenditure than those without dementia (Guijarro, San Román, Gómez-Huelgas et al., 2010; Eaker, Mickel, Chyou et al., 2002). The burden of healthcare costs has a huge impact on patients, particularly the elderly, their families and the nation as a whole.

The third issue is the study for the determination of the total cost of health expenditure among the elderly with dementia are lacking in Malaysia. Only a few recent studies in Malaysia have investigated the determinants of the risk factors of dementia, such as Hamid et al. (2010). The risk factors listed were older age, female gender, no formal education, ethnicity and very poor self-rated health and these were significantly correlated with dementia. Meanwhile, Razali R. et al. (2012) stated that only a low level of education was significantly associated with the elderly with MCI who attended the Universiti Kebangsaan Malaysia Medical Clinic (UKMMC). Limited physical activity, disability and environmental conditions also influenced the elderly with dementia on the risk

of falls (Ataollahi Eshkoor, Tengku Aizan Hamid, Siti Sa'adiah Hassan Nudin, & Yoke Mun, 2014). Hence, it is important to highlight that this study attempts to discover the determinants that influence the total cost of health expenditure among the elderly with dementia.

In the meantime, when viewed as the provision of government policy for the elderly in Malaysia, there are a few policies namely the National Elderly Policy, the National Action Plans for Elderly and the National Health Policy for Older Persons. Generally, all of these policies have emphasised a commitment by the Government to create self-sufficiency among the elderly, healthy ageing, active ageing and productive ageing to achieve rising living standards with increases in the quality of life and productivity in accordance with the 4th National Key Results Areas (NKRA)) and Vision 2020. However, there is no specific policy or strategy at the national level to make dementia a national health priority. The 2nd Edition of the Clinical Practice Guidelines (CPG) on the Management of Dementia (2009) provided by the Ministry of Health Malaysia has assisted clinicians in making evidence-based decisions on the management of people with dementia and their caregivers. Although there is no direct discussion about the economic burden of dementia in this guideline, the preventive strategies against the development of dementia and the provision of evidence-based guidance on the management of people with dementia and MCI were provided and will give an understanding of the impact of dementia on patients, caregivers, families and society.

In summary, the problem statement of this study emphasises that the prevailing trend of ageing will increase the prevalence of dementia and other comorbidities among the elderly and this will increase the cost of healthcare. With the absence of real data regarding the unit costs of providers and individuals among the elderly with dementia, it has been difficult to determine the cost of dementia and the burden of OOP health expenditure by the elderly with dementia from the patients and providers perspectives. Therefore, this study expects to provide the unit costs of providers, patients or individual's costs in terms of direct and indirect costs among the demented elderly in both the community and institutional settings.

1.4 Research Objectives

As alluded to in the issues above, the general objective of this study is to assess the direct and indirect costs of patients or individuals and providers in order to estimate the economic burden of dementia and its determinants among the elderly and the impacts on the nation as a whole. Meanwhile, the specific objectives are highlighted as follows:

Specific Objectives:

i. To estimate the direct and indirect costs incurred by the elderly with dementia in the community setting and the institutional setting in Malaysia.
ii. To examine the economic burden on the elderly with dementia individually and the national income as a whole.
iii. To investigate the determinants of the total healthcare cost among the elderly with dementia.

1.5 Contribution and Significant of the Study

The impact of dementia physically, psychologically and economically on patients, caregivers, families and finally society should be taken seriously and considered when devising public health policies for the future. Economically, the burden of the cost of dementia currently accounts for around 1% of the world's GDP and about 0.50% of the GDP in high middle-income countries. Consequently, even though the percentage of Malaysian total healthcare expenditure to GDP is less than 5 percent, the trend of dementia prevalence and its costs which have been discussed above have made an impact that is alarming and should be considered by individuals and society. By quantifying the costs of healthcare expenditure by the elderly with dementia using local and current data based on better underlying sources and an appropriate methodology can contribute to providing policymakers and society with valued information. Firstly, the main contribution is by providing new empirical evidence on the unit costs for providers, patients or individuals among the elderly with the three levels of severity of dementia in terms of direct costs and indirect costs for both outpatient and inpatient care.

Second, by estimating the burden and healthcare costs of dementia, there will be the potential to save costs if there has been early detection and intervention to reduce the prevalence of the disease or to lessen the level of severity or slow down its progression before it gets worse. Third, the determinants of the total costs among the elderly with dementia will be identified. Fourth, to our best knowledge, this is the first study that provides evidence on the costs of dementia using the local Malaysian data, as well as the determinants of healthcare costs among elderly with dementia.

Last but not least, the findings from this study are expected to attract the attention of the government and act as a wake-up call for them to become more concerned about the elderly who are at high risk of cognitive problems and to encourage the government to provide more appropriate health and social care facilities. It is hoped that this study will promote dementia as a

priority public health and social care issue in Malaysia as is the case in Australia, which was the first country to make dementia a national health priority in 2004. Another effort is the national dementia strategies that have been launched in France, South Korea, England, Norway and the Netherlands (Alzheimer's Disease Report, 2009). Also, these findings will hopefully be used by the authorities as guidelines to identify possible strategies to reduce the prevalence of ARDs and NCDs particularly dementia and all of its subtypes through appropriate preventative action, early detection or treatment plans. At the same time, the costs for the disease and burden of healthcare costs among the elderly can be shrunk whilst also promoting successful ageing.

1.6 Limitations of the Study

This study has some limitations that could influence the findings. First, the determination of dementia and its severity for the respondents was based on the Mini-Mental State Examination (MMSE) score solely. They were not diagnosed by a medical doctor for their dementia and severity but diagnosed with their comorbidities. Our expert group discussion (EGD) which consisted of psychiatrists and geriatricians from the selected hospitals, public health medicine specialists from the International Centre for Casemix and Clinical Coding, Faculty of Medicine, Universiti Kebangsaan Malaysia and senior officers from the Ministry of Health agreed to use the MMSE score as a proxy for the determination of dementia and its severity among the elderly in this study. The MMSE is a cognitive screening instrument that measures item recognition, orientation, memory, attention or concentration, calculation, language, and sentence formation capacity. The MMSE is a valid test and the most widely used screening instrument for cognitive impairment. Further discussion about the M-MMSE score is in Chapter 3.

Second, this study did not take into account the care time by the carers who assist the elderly in the activities of daily living (ADL), instrumental ADL (IADL) and the supervision of estimated informal caring costs. The indirect costs only consist of the opportunity cost of the time forgone by the respondents and carers. This is based on time lost and the days of absence whilst utilising healthcare facilities as an outpatient and inpatient respectively. For carers, these are the days lost due to accompanying and taking care of the elderly during hospitalisation.

Thirdly, in the provider's part, the costs were calculated based on the actual resources spent as stated in the expenditure book of the selected hospital as well as the number of staff and a full quota of equipment. This might underestimate the actual resources utilised for treating dementia. Besides that, the cost analysis was conducted based on the average cost per patient

and the length of stay was used as the cost driver for dementia costing. However, the methodology adopted in this study is acceptable and comparable internationally.

1.7 Organisation of Chapters

This introductory chapter provides an overview of the study, including the background of the study, the issues and the problem statement, the research questions, objectives and the significance of the study. The subsequent chapters follow with a Literature Review in Chapter 2 and the Research Methodology in Chapter 3, the Results and Discussion are in Chapter 4 and finally, the Conclusion, Policy Implications and Recommendations are in Chapter 5.

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