COMMUNITY DWELLING FRAIL OLDER PEOPLE IN AN URBAN SETTING IN MALAYSIA – PREVALENCE, HEALTHCARE UTILIZATION AND CAREGIVER BURDEN

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ABSTRACT

Introduction: With the rising life expectancies and declining fertility rates, Malaysia is moving towards the status of an ageing nation. Frailty increases incrementally with advancing age and these vulnerable older people are prone to dependency and poor health outcomes. These health outcomes contribute to an increased demand for optimum healthcare services and a robust familial support system. Therefore, the purpose of this research was to seek a better understanding on the prevalence of frail older people in Malaysia, factors that are associated with frailty, their patterns of healthcare utilization and the burden of care-giving experienced by their carer's.

Methods: Frailty status was determined using two measurement models; the Frailty Phenotype (FP) and the Frailty Index (FI) on a sample of 1040 community dwelling older people aged 60 and above residing in the district of Johor Bahru. A face to face interview with the older people was conducted to assess the frailty status and their health care utilization patterns. The caregiver that was present was required to self administer the Zarit Burden Interview. Multivariate regression analysis was applied to explore the correlates of frailty. The healthcare utilization pattern was described by frailty status. Ordinal regression models were used to evaluate the association between frailty and caregiver burden.

Results: The findings of this study highlighted that although the numbers that were categorized as frail was only (FI: 5.7 percent and FP: 3.0 percent), there are large numbers of pre-frail older people (FI: 67.7 percent and FP: 48.3 percent) residing in the community. The study also found that a past history of fall ($p<0.001$), abnormal upper ($p<0.05$) and lower body strength ($p<0.001$) and poor self rated health ($p<0.001$) were significant correlates to increasing levels of frailty ($p<0.05$). The results also showed that 35.0 percent of frail older people had a direct need for outpatient services as compared to 16.1 percent who were pre-frail and 14.2 percent who were robust. There

were also unmet needs among the frail and prefrail older people which were lack of transportation to access a healthcare facility (82.0 percent of frail older people) and poor perception of the gravity of their illness (43.0 percent of pre-frail older people). The frail older people were hospitalized 2.5 times more than pre-frail and 5.6 times more than robust older people. 45.5 percent and 49.2 percent of carers of frail and pre-frail older people experienced objective burden (worry and concern to provide optimum care) predominantly. The study results also highlighted that the caregivers of frail older people had 4.5 times the odds of experiencing mild to moderate levels of burden than the caregivers of robust older people.

Conclusion: This study provides a stepping stone for stakeholders of older people health to prevent or reverse the continuum of frailty by reducing falls and improving the nutritional status of older people in the community. Improving the provision of transport for frail older people to access the health system is warranted. Empowering caregivers with coping strategies and providing social and resources support such as respite care or day-care for the older people are approaches that can be explored to alleviate the caregiver's burden.

Key words: Frailty, Older people, Caregiver Burden, Healthcare Utilization, Frail Older people

ABSTRAK

Pendahuluan: Dengan kenaikan jangka hayat dan penurunan kadar kesuburan, Malaysia bergerak ke arah status sebuah negara penuaan. Kelemahan naik secara berperingkat dengan peningkatan usia dan ini menyebabkan warga tua terdedah kepada pergantungan dan hasil kesihatan yang kurang baik. Hasil kesihatan ini menyumbang kepada permintaan yang meningkat untuk perkhidmatan kesihatan yang optimum dan sistem sokongan kekeluargaan yang mantap. Oleh itu, tujuan kajian ini adalah untuk mendapatkan pemahaman yang lebih baik mengenai kelaziman warga-warga tua yang uzur di Malaysia, faktor-faktor yang dikaitkan dengan kelemahan, corak penggunaan penkhidmatan kesihatan dan beban penjagaan yang dialami oleh penjaga mereka.

Kaedah: Status kelemahan telah ditentukan dengan menggunakan dua model pengukuran; yang Fenotip Kelemahan (FP) dan Indeks Kelemahan (FI) ke atas sampel 1040 komuniti kediaman warga tua yang berumur 60 tahun ke atas yang tinggal di daerah Johor Bahru. Temuduga bersemuka dengan warga tua telah dijalankan untuk menilai status kelemahan dan corak penggunaan penjagaan kesihatan mereka. Penjaga yang hadir bersama diperlukan untuk menjawab borang soal-selidik 'Zarit Burden Interview'. Analisis regresi multivariate digunakan untuk meneroka korelasi kelemahan. Corak penggunaan perkhidmatan kesihatan digambarkan mengikut status kelemahan. Model regresi ordinal digunakan untuk menilai perkaitan antara frailty dan beban penjaga.

Keputusan: Hasil kajian ini menekankan bahawa walaupun nombor yang dikategorikan sebagai lemah hanya (FI: 5.7 peratus dan FP: 3.0 peratus), terdapat sejumlah besar pra-lemah (FI: 67.7 peratus dan FP: 48.3 peratus) yang tinggal dalam masyarakat. Kajian ini juga mendapati bahawa sejarah jatuh masa lalu ($p < 0.001$), kekuatan tangan yang tidak normal ($p < 0.05$) dan kekuatan kaki yang tidak normal($p < 0.001$) dan penilaian

kesihatan sendiri yang kurang baik ($p < 0.001$) menunjukkan kaitan yang penting kepada peningkatan tahap kelemahan ($p < 0.05$). Keputusan kajian juga menunjukkan bahawa 35.0 peratus daripada warga-warga tua yang lemah mempunyai keperluan langsung untuk perkhidmatan pesakit luar berbanding dengan 16.1 peratus yang pra-lemah dan 14.2 peratus yang masih teguh. Keperluan yang tidak dipenuhi antara warga tua yang lemah dan pra-lemah adalah seperti kekurangan pengangkutan untuk mengakses kemudahan penjagaan kesihatan (82.0 peratus daripada warga tua yang lemah) dan tanggapan salah betapa seriusnya penyakit mereka (43.0 peratus daripada warga tua yang pra-lemah). Warga-warga tua yang lemah telah dimasukkan ke hospital 2.5 kali lebih daripada warga pra-lemah dan 5.6 kali lebih daripada warga tua yang teguh. 45.5 peratus dan 49.2 peratus daripada penjaga warga tua yang lemah dan pra-lemah, kebanyakannya mengalami beban objektif (risau dan kebimbangan untuk menyediakan penjagaan optimum). Hasil kajian ini juga menekankan bahawa penjaga bagi warga tua yang lemah mempunyai sebanyak 4.5 kali kemungkinan mengalami tahap beban ringan ke sederhana dibanding dengan penjaga warga tua yang teguh.

Kesimpulan: Kajian ini merupakan batu loncatan untuk pihak-pihak berkepentingan kesihatan warga tua untuk mencegah atau membalikkan kontinum kelemahan dengan mengurangkan episod jatuh dan meningkatkan nutrisi warga tua dalam masyarakat. Memastikan penyediaan pengangkutan untuk warga-warga tua yang lemah untuk mengakses sistem kesihatan sangat diperlukan. Memperkasa penjaga dengan cara mengendali diri dan menyediakan sokongan sosial dan sumber-sumber seperti tempat penjagaan sementara atau penjagaan harian untuk warga tua adalah pendekatan yang boleh diterokai untuk mengurangkan beban penjaga.

Kata kunci: Kelemahan, warga tua, beban penjaga, penggunaan kemudahan kesihatan, warga-warga tua yang lemah

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LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
BMI	Body Mass Index
BSSK	Borang Saringan Status Kesihatan
CL	Kaigo-Lobo Checklist
COPD	Chronic Obstructive Pulmonary Disease
CRP	C-Reactive Protein
CSHA	Canadian Study of Health and Ageing
DALY	Disability Adjusted Life Years
DoS	Department of Statistics Malaysia
EB	Enumeration Blocks
EF	Elderly Frailty
EPF	Employees Provident Fund
EU	European Union
FCA	Federal Council on Ageing
FI	Frailty Index
FOD-CC	Frailty Operative Definition - Consensus Committee
FP	Frailty Phenotype
IADL	Instrumental Activities of Daily Living
IGF-1	Insulin-like Growth Factor 1
IL6	Interleukin 6
IMF	International Monetary Fund
KFI	Korean Longitudinal Study of Ageing (KLoSHA) Frail Index
LQ	Living Quarters
MMSE	Mini Mental State Examination
MoH	Ministry of Health Malaysia
MREC	Medical Research and Ethics Committee
NASCOM	National Association of Senior Citizens Malaysia
NCD	Non- Communicable Disease
NCE	Networks of Centres of Excellence
NHMS	National Health and Morbidity Survey
NICE	National Institute of Health and Care Excellence
NMRR	National Medical Research Registry
PLI	Poverty Income Line
ROS	Reactive Oxygen Species
SAGE	Study on Global AGEing and Adult Health
TILDA	The Irish Longitudinal Study on Ageing
TNFα	Tumour Necrosis Factor α
TVN	Technology Evaluation in the Older people
UMMC	University Malaya Medical Centre
Vo2 max	Maximal Oxygen Consumption
WHO	World Health Organization
ZBI	Zarit Burden Interview

LIST OF APPENDICES

CHAPTER 1: GENERAL INTRODUCTION

1.1 Introduction

Population ageing is gaining momentum in most countries with improvements in healthcare systems and delivery, declining fertility rates and higher socio-economic development in the country. This unprecedented demographic transformation that is happening globally will come with its fair share of elder health challenges and consequences for each country. One of the main driving forces of focus on older people health is due to the rising level of healthcare costs (Franzini & Dyer, 2008; R. Jones, 2013) and increased morbidity and mortality pattern (Babatsikou & Zavitsanou, 2010; Djernes, Gulmann, Foldager, Olesen, & Munk-Jørgensen, 2011) among the older people.

Among the many elder health conditions that have been the focus of geriatric health, frailty has generated considerable attention and scientific interest. The personal and public health interest of extended lifespan underscores the need for a better understanding of frailty. Frailty has not only been associated with adverse outcomes such as functional impairment, morbidity and mortality but has shown to have an impact on healthcare utilization and costs, caregiver burden, personal suffering and a poor quality of life (Lekan, 2009).

Another integral part of ageing is the family well-being, which today demands great attention. It has been traditional that the older person's primary caregiver is a member of his or her family and this family member has to take care of all the needs of the elder under his or her care. The burden of caring for the frail older people are higher especially if they are ridden with chronic conditions or disability which have shown a

rise in negative consequences such as stress and psychological strain during this care giving process (Vellone et al., 2011).

It is therefore important to ensure that the existing public policies and programs are sustainable in terms of providing optimum health and social services to meet the needs of this frail elder population.

This chapter will describe the demographics of ageing globally in Section 1.1.1, and Section 1.1.2 will introduce the concept of frailty in ageing. Section 1.2 describes the motivation behind this research followed by Section 1.3 which will outline the objectives of this research. The public health importance of doing this research among urban community dwelling older people will be described in Section 1.4 and the final section (Section 1.5) will describe the layout of this thesis.

1.1.1 Demographics of ageing

Ageing by definition is a process of growing old. This is a result from the demographic transitions such as decreased mortality and most importantly decreased fertility levels. It is projected that globally the number of older persons (aged 60 years or over) from the 1950s is expected to triple reaching to more than two billion people by year 2050 (Economic and Social Commision for Asia and the Pacific, 2002). The proportion of older persons was eight percent in the 1950s and is projected to exceed 21 percent by 2050 (Figure 1.1).

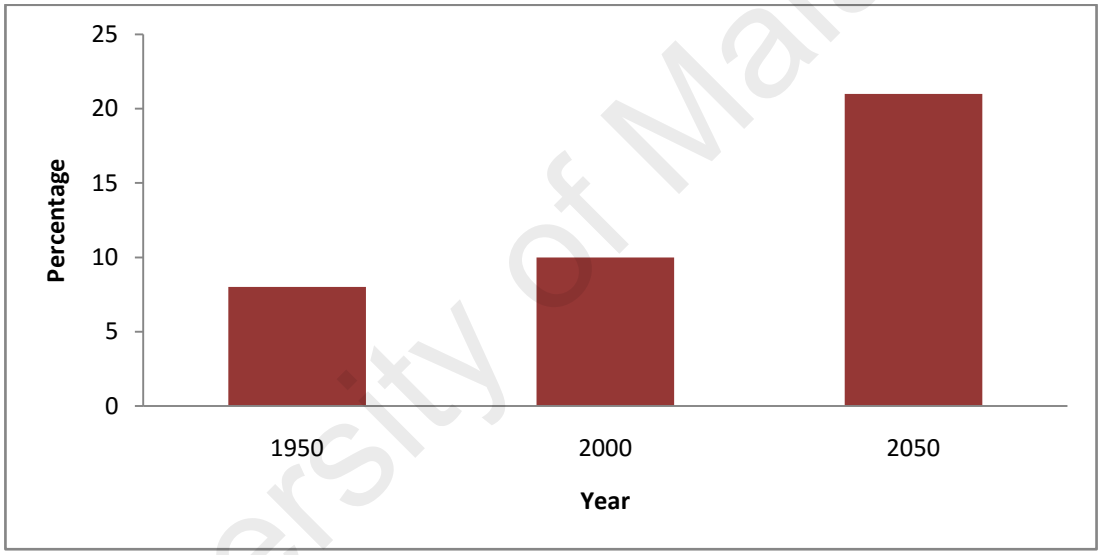

Figure 1.1 Proportion of population on 60 years and older: 1950-2050 world Source:(Department of Economic and Social Affair, 2001)

It has also been projected that the potential support ratio or otherwise known as dependency ratio in most countries will continue to fall from 12 in 1950 to almost four people in the working age group of 15 years to 64 years for every person aged 65 years and older in year 2050 (Figure 1.2).

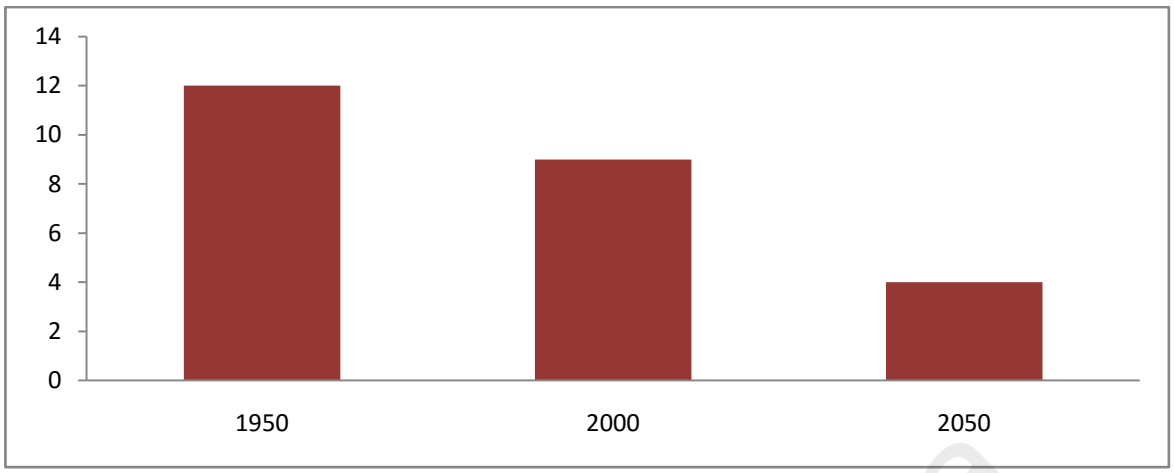

Figure 1.2 Potential Support Ratio: world Source: (Department of Economic and Social Affair, 2001)

The World Health Organization (WHO) published a report in 2014 showing that the gap between male and female life expectancies globally favours women (World Health Organization, 2014c). According to a report by the International Labour Organization, globally more women were likely to be widows, have less opportunity for education and with fewer years of work experience, leave them with lower access to a social security scheme (Internatinal Labour Organization, 2009). This heralds a bleak prospect for the older people especially women as the majority of older persons globally are women (Figure 1.3).

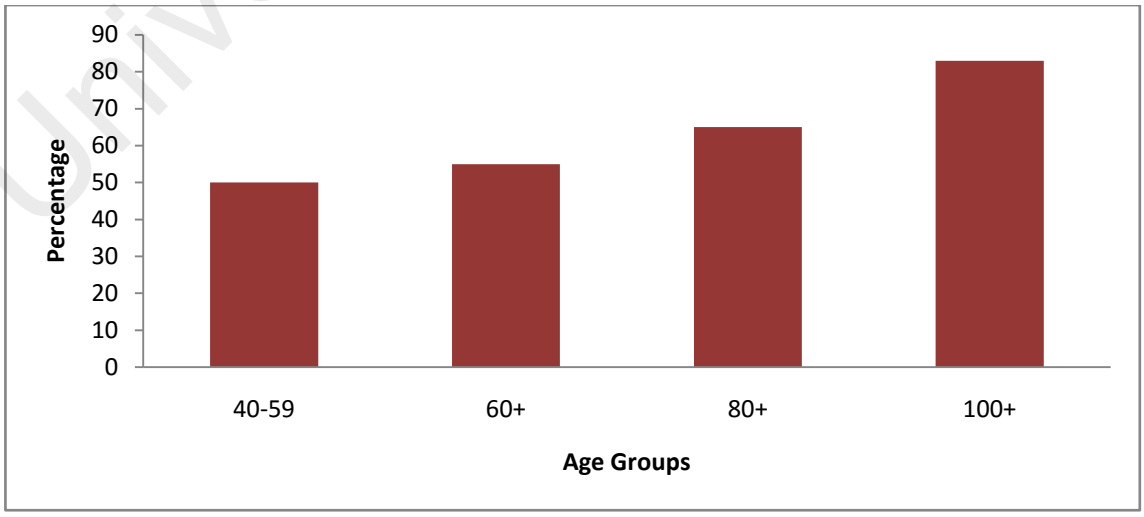

Figure 1.3 Proportion of women compared to men aged 40-59, 60+, 80+ and 100+ years: world 2000 Source: (Department of Economic and Social Affair, 2001)

It has been projected that in 2047, for the first time, the number of older persons is expected to exceed the number of children.

The concept of ageing has changed today due to the increase in life expectancy and each person has progressively more remaining years of life (Warren Sanderson & Sergei Sherbov, 2008). Older persons now prospectively have many more years to live though in some cases these years may not be lived in perfect health and therefore the healthcare decisions made individually or by the providers has to match this need. Warren Sanderson and Sergei Sherbov (2008) in their paper described this new notion as prospective age as opposed to chronological age which accounts for all the past years that one has already lived. This concept is important because it directly affects people in planning their lives and investing in their future, especially if the prospective age is high.

The operational definition for older people or the old varies from country to country usually determined by the complex demographic profiles and the political, social and economic climate of a country. However, most countries do try to conform to the chronological age of 65 as is adopted in most developed countries in relation to retirement age or receipt of pension. However, there are developing countries that have a different take on age; for example in the WHO Older Adult Health and Ageing Project the age of 50 is the cut off point for older adults (World Health Organization, 2010). While most of the time the cut-off age definition is associated with the time one can begin to receive pension, in developing countries like sub-Saharan Africa, the majority of elder persons living in rural areas have no formal retirement or retirement benefits. Therefore, in such developing regions the decision on age cut-off is usually dependent on a combination of relative life expectancy, functional and social definitions that replace pensionable age (World Health Organization, 2015). The Malaysian community

decided to adopt the operational definition of "60 years and over" that was proposed in Vienna by the United Nations in 1982 as a cut off for their senior citizens. Though this age may seem young for a developed nation, it seemed rather appropriate to adopt a lower age definition since gains in life expectancy in Malaysia have not yet matched the developed world (Krishnapillai et al., 2011).

Malaysia is now considered to have a sizable older population (Department of Statistics, 2000). The United Nations categorizes any country with 10 percent of population demography above the age of 60 as an ageing nation (Department of Economic and Social Affairs, 2002). It has been estimated that by the year 2020, the number of older people in Malaysia will increase to almost 10 percent of the total population.

1.1.2 Ageing and Frailty

World Health Day in 1999 celebrated old age and the concept of 'healthy ageing' to view the aged people as healthy contributors to the nation rather than as a burden. Considering that globally the awareness had started much earlier, developing countries are still far behind in managing their older people. Thankfully, in the last two decades frailty has been the buzzword of many researchers involved in ageing and many international bodies and organizations have mushroomed to provide a platform for this issue to be recognized as a pertinent issue in the world today. A large percentage of the worlds' older people live in Asia and this has forced Asian policy makers to wake up and invest time and money in their older population.

Work on ageing have focussed and highlighted various domains to have a more holistic approach in managing care for the older people. The domains that have stirred interests among researchers and clinicians range from genetics, age-related diseases, physiology,

biochemistry, behaviour and psychological aspects and public health perspectives of ageing just to name a few.

Among those ageing, there is a subgroup of people who are diagnosed and grouped to a special category called 'frail'. Frailty has gained popularity in the recent years in the field of gerontology as an important geriatric syndrome defining the functional capacity of an individual. Frailty is often equated with individuals who are functionally dependent on others for activities of daily living (Rockwood, Fox, Stolee, Robertson , & Beattie, 1994). Frailty is recognized as a progressive decline in physiological reserves affecting the older population (Mohandas, Reifsnyder, Jacobs, & Fox, 2011). Various definitions have been used to define frailty which clearly highlights complexity of the issue at hand. Though a validated definition is yet to be decided upon, there are mainly two schools of frailty study. One characterizes frailty as a multidimensional syndrome which encompasses several domains; physical, psychological, social and cognitive (R. J. Gobbens, K. G. Luijkx, M. T. Wijnen-Sponselee, & J. M. Schols, 2010) and the other focuses on physical characteristics to define frailty (L. P. Fried, Ferrucci, Darer, Williamson, & Anderson, 2004). Globally the burden of frailty ranges widely. Some countries register very high levels in their communities. A systematic review done by Collard, Boter, Schoevers, and Oude Voshaar (2012) concluded that the prevalence of frailty in the community varies enormously (range 4.0-59.1 percent). This variability in the frailty prevalence can be attributed to the operationalization of the frailty concept and the tool used to measure frailty subgroups.

Ageing has been associated with various geriatric issues such as falls (Mary E. Tinetti, Speechley, & Ginter, 1988), dementia (McCullagh, Craig, McIlroy, & Passmore, 2001), sarcopenia (Doherty, 2003; Hairi et al., 2010), urinary incontinence (Jackson et al., 2004) and frailty (Gallucci, Ongaro, Amici, & Regini, 2009; Torpy Jm, 2006). These

vulnerable subsets of frail older population have also been associated with disability and multiple co-morbidities (S.E. Espinoza & Fried, 2007; Gallucci et al., 2009), dependency (Abizanda et al., 2011), significant debility (L. P. Fried et al., 2001) and poor cognitive attributes (Rochat et al., 2010). Frailty is a dynamic process whereby there is a transition in the frailty status of an individual over time (Bergman et al., 2007a). This study shows that the process of frailty is considered reversible and subject to prevention. Hence, identification and pro-active actions to avoid or postpone adverse outcomes in life deserve emphasis.

In policy and public health domains the importance of identifying these frail older patients is now gaining attention due to its significant association to increased utilization of healthcare services (R. J. J. Gobbens & van Assen, 2012), higher risks of institutionalization and hospitalization (Boyd, Xue, Simpson, Guralnik, & Fried, 2005) and increased risks of morbidity and mortality (D. H. Lee, Buth, Martin, Yip, & Hirsch, 2010).

1.2 Motivation of study

The phenomenon of ageing is now an issue in most countries and Malaysia is not exempt from it.

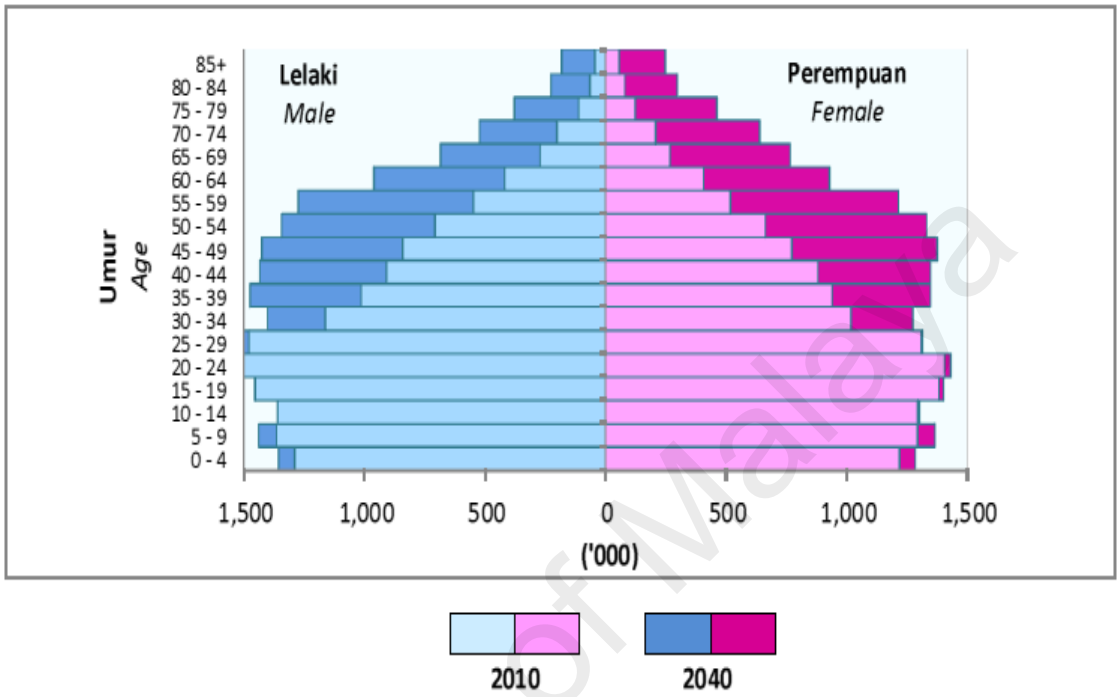

Figure 1.4: Malaysian Population Pyramid 2010 and 2040 Source: (Department of Statistics, 2012)

Figure 1.4 depicts the Malaysian Population Projection spanning from the year 2010 to 2040. The population pyramid which had a broad base figure in 2010 indicating high fertility levels shows a transition to an evolving broader apex by 2040 indicating a regressive pattern in birth rates and the growing older population in Malaysia. Regressive population pyramids have a smaller base which demonstrates a low birth rate and have convex slopes which reflect a low adult population mortality rate. The trends of population demography in Malaysia alert us that there are almost 10 to 15 years after the retirement age of 60 whereby one has to achieve successful ageing. Improvements in the healthcare system, has played a salient role in increasing the average lifespan of men to 71.9 years and 77 years for women (Ministry of Health,

2012). Rowe and Kahn (1997) recognized this state and describe successful ageing as a multidimensional concept encompassing the avoidance of disease and disability, the maintenance of high physical and cognitive function, and sustained engagement in social and productive activities. Based on the definition constructed above, factors such as physical, cognition, co-morbidities and disability that play a role in maintaining the lifespan and health of a person needs focus to ensure they reach their golden years.

As evidenced above, we are achieving longer life spans in Malaysia. However, the older people in Malaysia are also burdened with various health ailments and specific needs (Selvaratnam DP, 2012). This violates the first component required to achieve successful ageing. The results from a study done by Jang, Choi, and Kim (2009) point to the importance of focusing on socio-economic disparities and eliminating social inequalities among people to achieve successful ageing. In a study done by Sidik, Rampal, and Afifi (2004), the authors showed that 15.4 percent of the studied older people were functionally dependent and 22.4 percent of them were cognitively impaired. This revelation too then diminishes their hope of ageing independently.

Another perspective that is equally pertinent to old age is the socio-economic status of an individual to guarantee their smooth transition from adulthood to old age. Though Malaysia has notable progress in areas of economic and social development, it does not have sufficient social support services and financial schemes for older people compared to developed countries around the world. This will have a large impact on future healthcare costs and planning if we are to meet the demographic transition we are facing. An analysis into the various social protection schemes available for the older people in Malaysia showed that while the government provides benefits in cash and kind for the old through social welfare programmes, Malaysia still lacks a mandatory Public Pension Scheme (Abd Samad & Mansor, 2013). Currently, civil servants in

Malaysia are entirely dependent on a government pension plan that comes into effect with retirement at the age of 60 and the Employee Provident Fund (EPF) provides social protection coverage for all private sector employees and civil servants who had opted for it. The sustainability of the EPF to buffer their needs post retirement throughout their remaining lifespan is of concern. A study by the EPF in 2003 found that most retirees spend their entire EPF savings within three to five years of their retirement (Abd Samad & Mansor, 2013).

Globally, the impact of economic growth has impacted family institutions in profound ways and Malaysia is not exempt to this (Economic Planning Unit, 2013). The process of urbanization has caused working adults to migrate far from home, lower fertility rates and having insufficient funds to meet economic changes. The older people are the most likely group to get short-changed for care.

Even though we have a dearth of data on older people in Malaysia, there has been some work done which has highlighted the fact that Malaysia is no different than other nations when it comes to old age. However, data on frail older people in Malaysia is still scanty and a topic which only recently has been delved into with interest. Most of the rapidly urbanized states of Malaysia such as *Perak, Pulau Pinang* and *Melaka* show high proportions of senior citizens above six percent (Department of Statistics, 2000). Though the 2000 Malaysian Census found that the proportions of senior citizens were higher in the rural compared to the urban areas of Malaysia, with the rural to urban migration of the younger population for employment, the numbers of older people in the urban areas have also increased (Department of Statistics, Census 2010). A study done by Kooshiar, Yahaya, Hamid, Abu Samah, and Sedaghat Jou (2012) on living arrangements of older Malaysians found that 71 percent of the older people preferred

living with their children followed by 16 percent of them choosing to stay with their spouse.

Empirical evidence has shown us that healthy urban older people are relatively able to live independently and manage themselves (P. P. George, Heng, Wong, & Ng, 2014). However, this is not the same for the older people who are ill or frail (Vermeulen, Neyens, van Rossum, Spreeuwenberg, & de Witte, 2011). A population based study in urban China found that the maintenance of optimum health conditions among community dwelling older people and enhancing the concept of filial piety was crucial in efforts to improve their quality of life (Sun et al., 2015). Living in a busy urban setting with the added inability to be independent and/or mobile due to poor health conditions will cause problems in two important perspectives of their lives which is their family and the society at large. If there is a failure in these two pertinent scopes it is likely the lives of these older people will be adversely affected.

We do acknowledge that we have significant ageing population in this country, but we have a long journey ahead of us to reach levels of other ageing nations and therefore Malaysia needs to step up to this challenge and innovatively plan for a healthy and ageing society. Results from the 2011 National Health and Morbidity Survey found the state of Johor is one of the top three states in Malaysia with high prevalence rates of chronic illness (43.8 percent) after the Federal Territory of Putrajaya (57.5 percent) and Federal Territory of Kuala Lumpur (48.7 percent).[1]

[1] Malaysia is a federation consisting of thirteen states and three federal territories. Each state is divided into administrative districts which are then divided into '*mukims'* (subdivision of districts). The federal or central government located in Putrajaya, Malaysia is the ultimate authority body in Malaysia headed by the Prime Minister of Malaysia. The Prime Minister heads the cabinet (the executive branch of the government) consisting of a council of Ministers who are accountable collectively to the Parliament. Each of these elected Ministers are responsible for the various sectors responsible for the well-being of the country.

This will lead to high healthcare utilization and needs among the population of Johor. The state of Johor had 7.1 percent of its population above the age of 60 in the year 2010 and the highest numbers of older people come from the district of Johor Bahru which is also the state's capital city (Table 1.1).

Table 1.1 Percentage of older people aged 60 and above in the state of Johor (Department of Statistics, Malaysia, Census 2010)

Districts in Johor	Total number of people aged 60 and above	Total Percentage Contribution (%)
Johor Bahru	74985	35.7
Kulaijaya	15182	7.4
Batu Pahat	25882	12.3
Kluang	21711	10.3
Muar	24125	11.5
Kota Tinggi	6914	3.3
Segamat	11326	5.4
Pontian	11121	5.3
Ledang	15776	7.5
Mersing	2778	1.3

The district of Johor Bahru was chosen for this study because of its high proportion of urban older people and the high level of migration that occurs in that State which will have an impact on the lifestyle and well-being of their senior citizens. Johor Bahru has a high level of in-migration of the younger workforce from other states and external in-migrants from neighbouring countries (Department of Statistics, 2000).

The perspective of family time and care giving is also a topic of concern in the district of Johor Bahru due to the large numbers of Malaysian citizens who commute to the neighbouring country Singapore to seek employment leaving behind their family and dependents (World Bank Report, 2011). Conducting research among the older people and furthermore associating it to outcomes such as healthcare utilization can help policy makers contain escalating costs of healthcare by focusing on target oriented preventive measures for this vulnerable group in their pre-frail state and intensive rehabilitative and social support measures for those who have become frail.

1.3 Objectives of Study

There is paucity of work done on frailty in Malaysia and currently this field in geriatrics is gaining attention among academics and clinicians. This study intends to unravel the burden of frailty, its potential correlates and its impact on healthcare utilization in Malaysia. Increased healthcare needs due to frailty requires continuous support, money and time which will directly increase the burden among caregivers of these frail older people which will also be explored in this thesis.

The objectives of this study are:-

a) To critically review the concept and measurement of frailty among the older people.

b) To review public policies governing the older people and their health in this country in order to identify opportunities for development of policies to prevent development of frailty among the older people.

c) To validate appropriate tools to assess frailty and caregiver burden to be used among older people living in an urban community.

d) To estimate the burden and correlates of frailty among older people who reside in Johor Bahru.

e) To explore the association between frailty and patterns of utilization of healthcare services.

f) To estimate the burden of care among caregivers of frail older people and to identify factors playing a significant role in this association.

g) To come up with relevant policies which incorporate frailty among the older people for Malaysia.

1.4 Public health significance of study

Malaysia is a country which is known to be strong in the old Asian value of filial piety (Loo See & Jee Yoong, 2013). Although the cultural value of caring for their older people remains, the children tend to be torn between providing for their young and their moral obligation to care for their parents (Alavi, 2013). This care giving process can further be complicated if the elder is suffering with illness or disability due to the need for more time, money and commitment from these caregivers. A study done by Zainuddin, Arokiasamy, and Poi (2003) identified that among those attending a geriatric clinic in an urban hospital in Malaysia, 31 percent of the caregivers experienced high care-giving burden. A meta-analytic comparison of studies on causes of burden when caring for older people found that depression, physical and financial burdens were the commonest form of distress reported by carers (M. Pinquart & Sorensen, 2011). In the process of upholding their cultural values to provide care for their frail and ageing parents and juggling their daily responsibilities these caregivers are susceptible to high levels of stress and negative emotions which can be assessed by their level of burden.

The second scope is the impact of frail older people in the community on the society. The Malaysian National Health and Morbidity Survey 2011 (NHMS) on utilization of healthcare services concluded that the two extreme age-groups, namely 0-4 (23.8 percent) and above 75 (22 percent) years had significantly higher utilization of outpatient services when compared to ages five to 74. The highest prevalence of hospitalization was also among those aged above 60 as compared to those below the age of 60 years (Institute of Public Health, 2012).

This survey also reported a high overall prevalence of non-communicable disease among the older people above the age of 60 with the highest prevalence among the old-old group (above the age of 75) (Institute of Public Health & Institute of Health Systems Research, 2012). The prevalence of outpatient and in-patient healthcare utilization for

the old-old was the highest at 22 percent and 17 percent respectively as compared to all other age groups in 2011(Institute of Public Health, 2011). The urban older people have their fair share of lifestyle challenges such as loneliness, poor support system, lack of financial stability and emotional strain (Selvaratnam & Tin, 2007). The condition of being frail will further exacerbate these challenges in them.

The complexities of ageing issues compounded by high healthcare costs and multidisciplinary healthcare services can affect the society as a whole. A shift in the economic landscape is inevitable due to the high utilization rates of medical, social and welfare services. Understanding the patterns and barriers of healthcare utilization can provide a framework to initiate improvements in the system to provide better care for these older people and avoid resource wastage or underutilization.

1.5 Layout of thesis

This chapter introduced the demographics of aging in Malaysia and motivation behind this study. This will be followed by **Chapter 2** which creates an understanding on the pathophysiology of frailty and the various definitions on frailty available. The various strategies to measure frailty and the complexities to measure this concept will be highlighted. **Chapter 3** then provides an over view of the policies that govern our older people in Malaysia and to analyse how these policies have been translated to practice. It is of immense value to understand the policies that exist today to identify the best possible way to merge the current research topic with the policies to ensure that they are applicable and if mismatched to call for a revision of the same policy to ensure integration of evidence based care. In **Chapter 4** the methodology applied to achieve the objectives and the process on data management is explained in depth. The various instruments used and variables chosen are described. Validating the study instruments which are the two frailty assessment tools namely; the multidimensional Frailty index

(FI) and Fried's Physical Phenotype (FP) and the caregiver burden tool known as the Zarit Burden Interview (ZBI) is described in **Chapter 5**. The frailty assessment tools are tested for internal reliability and validity properties for this study population. The validation of the frailty assessment tool was based on its reliability, content and constructs validity for the study. The chapter also includes a discussion on the choice of frailty assessment tool used in this study acknowledging the fact that they are two separate concepts of tool which are not directly comparable. **Chapter 6** takes us through a description of the prevalence of frailty and its probable correlates which will give an insight into the burden Malaysia faces and the factors that are contributing to the phenomenon. In **Chapter 7**, the results highlight the patterns of healthcare utilization among the older people especially among those in the pre-frail and frail subgroup as this will help in identifying the targeted measures and resources that are needed to assist these special groups to access healthcare facilities and fully utilize the benefits that they are entitled to. The burden of care giving for the older people is a recognized issue today and the burden gets exacerbated when the older people is ridden with a syndrome such as frailty. **Chapter 8** depicts the prevalence of burden of care giving among the carers of frail older people and to ascertain the probable risk factors that may contribute to this burden further. In **Chapter 9** all the results and findings obtained through this study are aggregated to engage in a discussion to improve our body of knowledge on the topic concerned and constructively find alternatives and opportunities to provide holistic care for the older people and provide an insight for our policymakers to draft policies that are targeted. This final chapter will also conclude the research findings, and incorporate appropriate recommendations for future work. The findings of this study will provide an avenue for all stakeholders involved in older people care to identify and understand factors that influence the process of frailty and in turn aid in the improvement of their services that are available for the older people in Malaysia.

CHAPTER 2: CONCEPT OF THE FRAIL ELDER AND RELATED MEASUREMENT ISSUES

2.1 Introduction

Since the early 70s, the number of people above the age of 60 has been steadily rising. Elder frailty being one of the most significant problems afflicting the geriatric population has now become a public health concern. The term elderly frailty (EF) was proposed by the Federal Council on the Aging (1978) to indicate older people characterized by physical disability and affective compromise living in an environment being structurally and socially disadvantageous (Malaguarnera, Vacante, Frazzetto, & Motta, 2013). This included the need for assistance of daily living and adequate social support.

Analyses into gerontological research conducted over the last two decades show that the term frailty has not only taken different conceptualizations and meaning but also includes several contradictions (Rockwood, 2005a). Researchers, policy-makers, administrators and geriatric healthcare providers have generally agreed that frailty is an important concept in the care of the aged especially in terms of care giving and healthcare system, but the controversies surrounding this topic still remains (Bergman et al., 2007a).

Section 2.2 of this chapter will start with an understanding on the pathophysiology of frailty. From this pathogenesis of frailty various definitions have been derived to operationalize the concept of frailty today which will be highlighted in Section 2.3. Section 2.4 will describe the various measurement strategies used by researchers today to operationalize this definition of frailty. This section will be followed by a review (Section 2.5) of the complexities faced when measuring frailty in a population. Section

2.6 will conclude with a section on why measuring frailty is important and beneficial in the geriatric world today. Section 2.7 summarizes the whole concept of frailty for a comprehensive understanding on this topic of interest.

2.2 Pathophysiology of frailty

Measuring frailty is a complex process but recognizing the role of physiological decline that occurs during ageing can help us understand the evolution of frailty better. It is a common observation that one's' chronological age does not increase in tandem with the biological age of a person. Chronological age refers to the actual time the person has been alive whereas biological age refers to how old that person seems or feels. A landmark study in New Zealand found that young individuals below the chronological age of 38 had a wide range in their biological age ranging from ages 30 to 60 (Belsky et al., 2015). This simply means that even young individuals have declining physiological reserves which contribute to the rapid ageing process. This wide variation in the physiology of ageing seen among the older people explains why ageing is poorly defined. Nevertheless, broadly the pathophysiology of ageing is governed by three factors; physical, psychological and social.

Most studies in frailty have recognized that frailty is a physiological decline that occurs as age increases (Collerton et al., 2012). Frailty is not only a physiological decline but is accompanied with a deregulation of multiple systems such as the muscular, neuroendocrine and immune system (Cohen, 2000). Even though ageing involves every cell in a person, the homeostasis and integration of these three biological systems have been shown to play a critical role in the ageing process since the late 80s (Meites, Goya, & Takahashi, 1987).

The association between sarcopenia and frailty was initially investigated using the physical frailty definition used by L. P. Fried et al. (2004). This hypothesized pathway of frailty (Figure 2.1) explains that sarcopenia (which is a loss of muscle mass) is central to the cycle of frailty where resting metabolic rate, chronic under-nutrition and energy expenditure reinforce the cycle. This in turn influences insulin sensitivity, bone

mass (vitamin D levels), strength, gait speed, power and maximal oxygen consumption (volume oxygen: VO_2 max) in the pathway to disability and dependency. Although frailty frequently exists concurrently with disease and disability, Fried explains that they are distinct and independent features present in an individual (L. P. Fried et al., 2004).

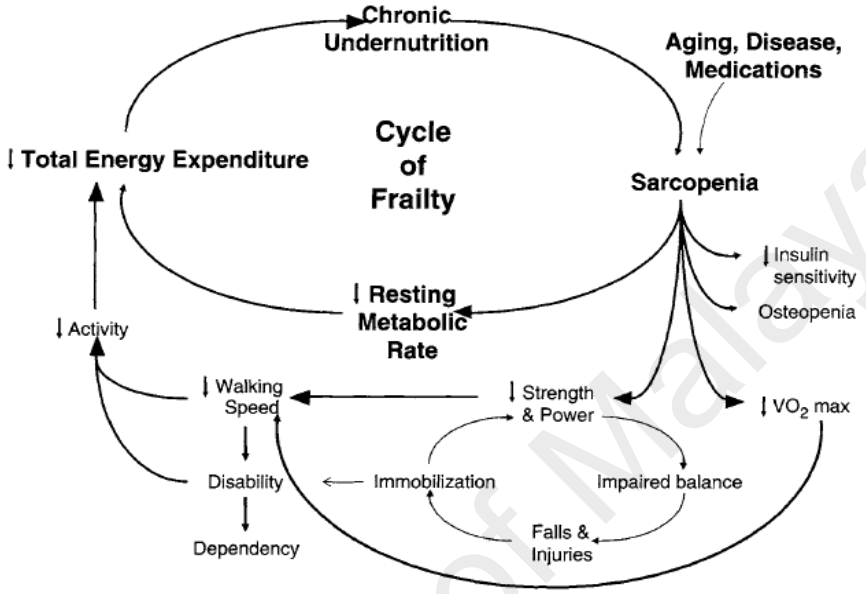

Figure 2.1 Cycle of frailty hypothesized by Fried et al. 1991

A domino effect of this research led to significant findings in the cycle of frailty; the discovery of insulin like growth factor 1(IGF-1) and its connection to muscle strength (J. E. Morley, Baumgartner, Roubenoff, Mayer, & Nair, 2001) and interleukin 6 (IL-6) ; an inflammatory gene (S. Leng, Chaves, Koenig, & Walston, 2002; S. X. Leng, Xue, Tian, Walston, & Fried, 2007) as key players connected with ageing.

Elevated C-reactive protein (CRP), interleukin levels (IL), tumour necrosis factor α (TNF-α) and abnormal coagulation which are features of chronic inflammation are considered to play a salient role in the pathophysiology of frailty (Vivian Shen, Li-Kuo Liu, & Liang-Kung Chen, 2011 January 19-20). The inflammatory markers that have been linked with respect to ageing such as the cytokine interleukin 6 (IL6) and the acute phase reactant C-reactive protein (CRP) have demonstrated an association with increased levels with increments in markers of frailty. Some studies have shown

correlations of IL6 with the subsequent development of disability and mortality (S. X. Leng et al., 2007). Figure 2.2 depicts the work done by Yao, Li, and Leng (2011) to support the role of the immune system deregulation in the pathogenesis of frailty.

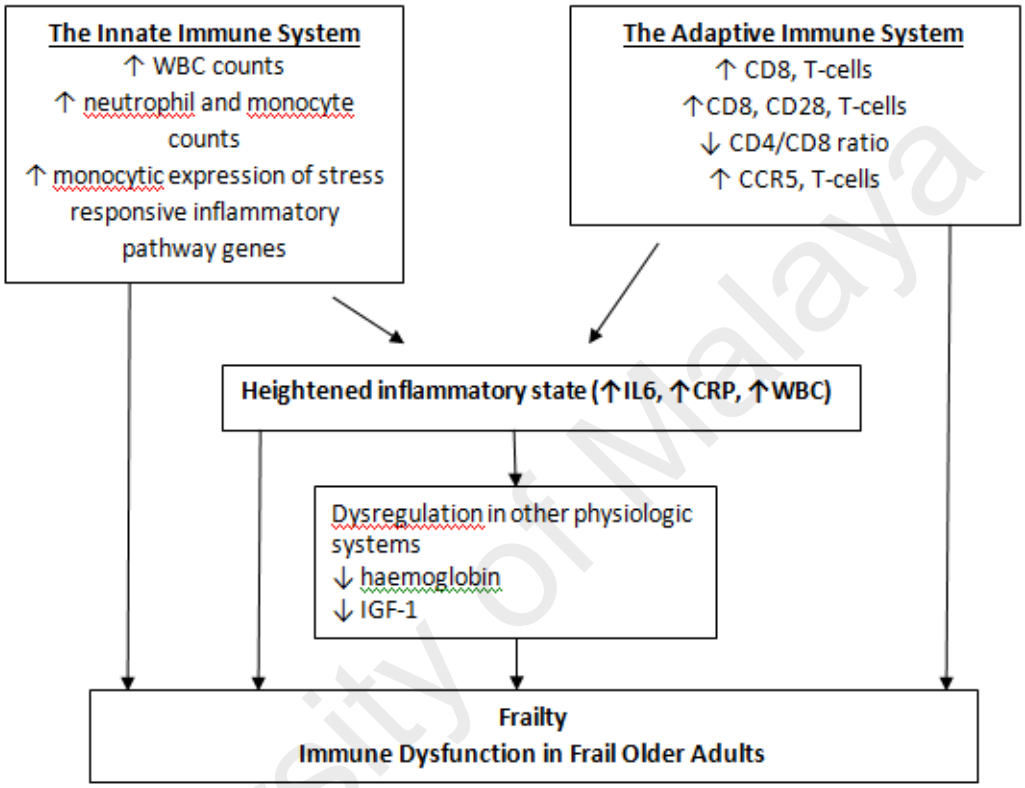

Figure 2.2 Inflammation and immune system alterations in frailty. CCR5-Chemokine CCreceptor5, IGF-1 insulin like growth factor 1, WBC –white blood cells (Source: Yao et al. (2011)

Other factors that play a role in the pathogenesis of frailty are gene, environment and lifestyle. J. E. Morley, Haren, Rolland, and Kim (2006) described that the heightened inflammatory condition can be precipitated by disease, stress, impaired muscle function leading to disability and inability to exercise. This viciously precipitates pain which further limits a person's activity level.

The inability to develop adequate muscle power is a known feature of frailty. Recently, the role of vitamin D and the anabolic hormone testosterone in improving muscle mass

and function have been explored (J. E. Morley, 2003). It was found that though supplementation of vitamin D did show some benefit among the frail, the optimum therapeutic dose was yet to be established (Campbell & Szoeke, 2009). A meta-analysis of 11 trials demonstrated that testosterone replacement therapy significantly improved muscle strength in older men (Ottenbacher, Ottenbacher, Ottenbacher, Acha, & Ostir, 2006). However, despite improved muscle strength, functional improvement showed conflicting results in frail individuals (Kenny et al., 2010).

High oxidative stress in the body has also been implicated as a factor in maintaining health, ageing and age-related diseases (Rahman, 2007; I. Chien Wu, Shiesh, Kuo, & Lin, 2009). Though, oxygen is imperative for life, imbalanced metabolism and excess reactive oxygen species (ROS) generation develop into a range of disorders such as Alzheimer's disease, Parkinson's disease, ageing and many other neural disorders (Uttara, Singh, Zamboni, & Mahajan, 2009). An understanding of the mediators in the pathway of frailty can serve as a guide for methods to ameliorate the process of ageing.

2.3 Definition of frailty

There are several key processes in our multi-organ system such as musculoskeletal, endocrine, immune, hematologic and cardiovascular that either directly or indirectly contribute to the pathogenesis of frailty (H. Li, Manwani, & Leng, 2011). These multifactorial aetiology and mediators that are connected to this ageing process have led to the many definitions of frailty we have today.

Talking about frailty makes us imagine wrinkled old individuals falling apart and unable to fend for themselves. However, when we scrutinize further we see various combinations of identities that make up the people who may be old, dependent and ridden with illness. This makes it an arduous task on describing the basic ingredients

required to fulfil the frailty definition or criteria. Frailty which originates from the Latin word '*fragilitas*' is defined as a condition of being weak and delicate (Oxford Dictionary, 2010).

Geriatricians have a common notation whereby the term "frailty" is related to a range of phenotypes such as muscle weakness, bone fragility, loss of weight, vulnerability to infection and trauma, and diminished physical capabilities and any of these conditions in combination occur in parallel at one point in time (J. Walston et al., 2006). This cycle of physical vulnerability is largely evident from the pathophysiology described in the section earlier. Frailty being a geriatric syndrome and its obvious importance in the clinical context, a clinical definition – "Frailty is theoretically defined as a clinically recognizable state of increased vulnerability resulting from aging-associated decline in reserve and function across multiple physiologic systems such that the ability to cope with every day or acute stressors is compromised." The definition was established by Q.-L. Xue (2011). Ahmed, Mandel, and Fain (2007) in their paper describe a stage in frailty called 'homeostenosis' whereby the body is inept to physiologically respond to acute stress resulting in a condition where frailty is a product of "excess demand imposed upon reduced capacity".

The early definitions on frailty were based mainly on the scientific basis of the pathophysiology occurring in frailty but with substantial increase in research on frailty and the interdisciplinary care new approaches were needed to understand the concept of frailty that has evolved (Karunananthan, Wolfson, Bergman, Beland, & Hogan, 2009). Researchers have applied different approaches in describing the concept of frailty by including domains such as physical characteristics, social and cognitive factors (R. J. Gobbens, van Assen, Luijkx, & Schols, 2012; L. Rodríguez-Mañas et al., 2013).

The most popular definition on frailty was proposed by Linda Fried "Frailty is a process whereby a gradual decline in physiological reserves results in increased susceptibility to external stressors". From the 22 articles systematically reviewed as part of the Canadian Initiative on Frailty and Aging the prevalence of frailty ranged from 5 to 58.0 percent (Sternberg, Schwartz, Karunananthan, Bergman, & Mark Clarfield, 2011). This review found that physical function, gait speed and cognition were the most commonly used identifying components of frailty however the role of cognition, mood and disability requires clarification whether it should be a component or an outcome of frailty. This definition was popularized in the Cardiovascular Health Study and included only physical parameters and specifically excluded co-morbidities and disabilities as separate entities from frailty (L. P. Fried et al., 2001). This gave rise to a physical definition of frailty.

However, to reflect the constantly changing nature of frailty and the multidimensional domain influencing it, another group of authors defined frailty as 'a dynamic state affecting an individual who experiences losses in one or more domains of human functioning (physical, psychological, and social), which is caused by the influence of a range of variables and which increases the risk of adverse outcomes' (R. J. J. Gobbens, K. G. Luijkx, M. T. Wijnen-Sponselee, & J. M. G. A. Schols, 2010). This "accumulation of deficits" model included co-morbidities and disabilities as part of the frailty syndrome.

Defining frailty has become a controversial subject with various groups supporting mainly two different conceptual framework represented by Fried's Phenotypic definition (mainly physical phenotype) or the Rockwood's frailty index of deficit accumulation as the primary operational definition to measure frailty in a population. A systematic review done by Borges and Menezes (2011) found that in defining frailty in

research there was a predominance of operational definitions that used only physical markers. This review included 25 articles however with such variability in the studies available globally there was still no standard definition or agreement of the markers of frailty syndrome from this review.

Recently, there is growing debate on newer definitions based on frailty subtypes such as cognitive frailty, psychological frailty and social frailty. The value on establishing new subgroups and defining them is still unclear but it does not equate to explaining the full conceptual model of frailty (Leocadio Rodríguez-Mañas & Sinclair, 2014). Although the clinicians and the science based researchers have different perspectives in defining this vulnerable state, highlighting the need for a conceptual definition and understanding was a common goal.

The contentious issue here is to decide what components are to be included in a frailty definition. A systematic review done by Sternberg et al. (2011) identified that the most common identifying factors for frailty were physical functioning, gait speed and cognition. This study also highlighted the most common outcomes researched which were death, disability and institutionalization. Short term outcomes such as falls and hospitalization were also gaining interest among many authors (Ávila-Funes et al., 2009; Ravaglia et al., 2008).

The innumerable ways to define frailty described in literature exemplifies the complexity of this geriatric syndrome. More recently, a consensus group from six international societies convened in Orlando, Florida in December 2012 to discuss on a specific form of frailty; namely physical frailty. It was of agreement that older persons above the age of 70 with significant weight loss (five percent or more than their original weight) due to a chronic disease should be screened for frailty (John E. Morley et al.,

2013). Rockwood (2005b) called for a consensus to find a valid and successful definition of frailty which needs to be multi-factorial and computationally tractable.

In response to the demand for a consensus on the definition, the Frailty Operative Definition-Consensus Conference project aimed to use a Delphi consensus building project to arrive at a comprehensive definition agreed globally (L. Rodríguez-Mañas et al., 2013). This study also concluded that there is value in screening for frailty and assessments on frailty should include six main domains such as assessment of physical performance, gait speed and mobility, nutritional status, mental health and cognition. However, that study showed a low level of consensus regarding proposed pathways to achieve an operational definition. Although research on frailty has its merits but a lack of consensus as evidenced in the review done by Karunananthan et al. (2009) makes it a critical problem.

The definitions above attempt to elucidate the heterogeneity of the condition present among the older people for the benefit of clinical practitioners and policy makers (Collard et al., 2012). As early as the 70s, The Federal Council on Ageing (FCA) in the United States introduced the concept of frailty and highlighted the need for support services for this group of older people (De Witte et al., 2013). Since then the cascade of research linking frailty to various adverse events has been flooding the geriatric field. This painstaking and unrelenting search for a definition is essentially geared toward finding a clinically usable definition which would allow risk stratification for their patients and for the policy makers and researchers this would mean utilizing adequate resources on validated interventions to treat or prevent frailty.

2.4 Measurement strategies of frailty

Despite the controversies in the definition, the need to screen for frailty was still a priority among geriatricians as frailty has been linked with other geriatric syndromes such as incontinence, delirium, syncope, urinary incontinence and falls (Inouye, Studenski, Tinetti, & Kuchel, 2007). Over the years, the lack of consensus on definition has led to most instruments stemming from three schools of thought (Rockwood, Hogan, & MacKnight, 2000):-

a) Fried's phenotypic definition of frailty (Frailty Phenotype)
b) Rockwood's accumulation and deficit indexes (Frailty Index)
c) Clinical judgment based frailty index

These further are divided into tools that do not need the availability of a geriatrician such as Frailty Phenotype and the Frailty Index and tools that need the presence of one which is the clinical judgment index.

The phenotypic definition of frailty as described by (Linda P. Fried et al., 1991), was validated in a study population derived from the Cardiovascular Health Study cohort. Frailty was defined as a clinical syndrome in which three or more of the following criteria was present; unintentional weight loss, self-reported exhaustion, grip strength, slow walking speed and low physical activity (L. P. Fried et al., 2001). The older people who were frail were individuals who had three or more positive criterion using the phenotypic definition of frailty. Those who had one or two positive criteria were categorized as pre-frail and the rest robust. This form of measurement focused solely on physical parameters of frailty and was called the 'Fried Phenotype Scale' (L. P. Fried et al., 2001).

The hypothesized cycle of frailty by Fried and colleagues provided the foundation on which components in the cycle when measured would identify the frailty syndrome (L.

P. Fried et al., 2001). Some instruments measuring physical frailty included co-morbidity and physical disability (Cacciatore et al., 2005; M. T. Puts, Lips, & Deeg, 2005b) highlighting the common occurrence of these conditions among the older people. The need to incorporate co-morbidity or disability in the tool was debatable as Fried argued in her paper that although in many cases co-morbidities and disabilities may coexist, they are independent and distinct from one another (L. P. Fried et al., 2004). This distinction was eloquently explained in the Cardiovascular Health Study which found that the proportions of community dwelling older people who were frail and with diagnosed co-morbidity and disability was only 21 percent (Figure 2.3).

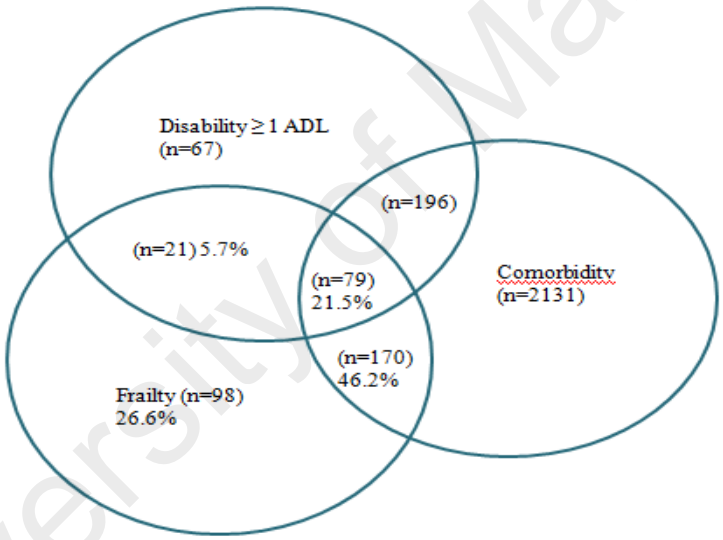

Figure 2.3 Prevalence—and overlaps—of co morbidity, disability, and frailty among community-dwelling men and women 65 years and older participating in the Cardiovascular Health Study (Source: (L. P. Fried et al., 2004))

There were also several spectrums of frailty with neither co-morbidity nor disability coexistent indicating that the three conditions can overlap with each other but is not a prerequisite to co-exist. Looking at the overlap of co-existing conditions in the Cardiovascular Health Study, higher numbers of participants in that had coexisting comorbidity and disability as compared to frailty and disability (Figure 2.3). Data from The Older Persons and Informal Caregivers Minimum Dataset across Netherlands found

that 31.9 percent of elderly living independently at home and 68.3 percent of elderly in a care home had frailty, multimorbidity and disability (Lutomski et al., 2014). It is understandable why most frailty measures measure the physical component of an older person since the presence of frailty significantly predicts disability in older pesons (Boyd et al., 2005).

Most early definitions of frailty were confined to models based on threshold limits, which then made way for a more dynamic model (Kenneth et al., 1994). In 2001, Minitski, Mogilner and Rockwood concurred that accumulation of deficits was a macroscopic variable that reflects general properties of ageing at the level of the whole organism rather than any given functional deficiency hence it can be used as a proxy measure of ageing. The dynamic model of frailty in the older people was a description of balance between assets and deficits which determines the independence of a person in the community (Mitnitski, Song, & Rockwood, 2004). The global measure of frailty described by Rockwood et al. (2005) enumerated almost 70 variables that could operationalize the frailty factor.

The issue with this global measure of frailty is that it assumes that all deficits are of equal importance (unweighted) and measurement was time consuming. As an improvement to the model by Rockwood, the British Frailty Index was proposed which was to add weight to the various variables to depict the spectrum of frailty (Kamaruzzaman, Ploubidis, Fletcher, & Ebrahim, 2010).

During the second stage of Canadian Study of Health and Aging (CSHA) a 7 point Clinical Frailty Scale was developed which relied heavily on clinical judgment which may vary from user to user and is only beneficial for clinicians experienced in the field of elder care (Rockwood et al., 2005). The Clinical Frailty Scale ranges from a score of 1, that depicts one who is very fit, robust, energetic, well motivated and exercises

regularly to 7, depicting those who are completely dependent on others for activities of daily living or terminally ill. The inter-observer reliability of this type of tool is likely not satisfactory due to differences in interpretations and measures by each clinician (R. E. Hubbard, O'Mahony, & Woodhouse, 2009).

Further measures that were developed were mostly physical measures which were represented as a single marker such as grip strength (H. Syddall, Cooper, Martin, Briggs, & Aihie Sayer, 2003), walking speed (H. E. Syddall, Westbury, Cooper, & Sayer, 2014), and the ability to stand-up from chair, and gait speed (Schoon, Bongers, Van Kempen, Melis, & Olde Rikkert, 2014 309). Singular subjective measures used scores from personal evaluation of one's own health status such as 'self rated health' to predict frailty in the older people (Ebrahimi, Dahlin-Ivanoff, Eklund, Jakobsson, & Wilhelmson, 2015).

2.5 Complexities in measuring frailty

There is a wealth of research that can be obtained by quantifying the experience of frailty in older people. Though frailty is essentially a dynamic, individual and qualitative experience, translating this experience into a measurable unit may allow one to understand the pathway and advocate interventions or preventive strategies during the disease evolution. Authors have proposed hypothesis and ideas on the pathway of frailty leading to many theoretical definitions in the past (de Saint-Hubert & Swine, 2007; Levers, Estabrooks, & Ross Kerr, 2006). Gradually, the need for an operational definition to conceptualize the disease in a quantitative manner took precedence (R. J. J. Gobbens et al., 2010). These operational definitions were described by scales or indices accompanied by some measurement parameters. These scales usually reflect the changeability of frailty over time by the interaction of several factors in the physical, social and psychological domains. Admittedly, there are several variations in the

operationalization of frailty measurement among authors that render comparison of findings challenging and the added realization that none of these measurements appear to qualify as a 'gold standard' (Bouillon et al., 2013).

The review by Bouillon et al. (2013) identified at least 27 different measures of frailty. However, frailty phenotype scale developed by Fried (L. P. Fried et al., 2001) was favoured by most investigators followed by the Frailty Index proposed by Rockwood (Rockwood et al., 2005). Co-morbidities and disability have been included into some scales acknowledging the similarities in their biological pathways (M. Brown, Sinacore, Binder, & Kohrt, 2000; Murad & Kitzman, 2012). Other domains that have been included in measurement tools are the nutritional state of the older people due to overwhelming evidence from research based on nutrition, disease evolution and muscle mass and strength in the older people (Kelaiditi, Guyonnet, & Cesari, 2015; Oehlschlaeger, Pastore, Cavalli, & Gonzalez, 2014). Similarly, nutritional deficiency does have some impact on the frail older people but as suggested by Boulos, Salameh, and Barberger-Gateau (2015) they are two related but distinct concepts that share common determinants in the population. In fact, being frail could precede the occurrence of malnutrition causing the older people to spiral further downward. The concern is when one or more of these entities coexists, additive or synergistic effects may be seen on adverse outcomes.

The diversity in measuring frailty is not limited to only different operational definitions but different scoring mechanisms to define each subgroup; robust, pre-frail and frail. This finding was highlighted in the systematic review done by N. M. de Vries et al. (2011) on instruments available to measure frailty. The scoring range and classification of frailty was so diverse that comparability between the various tools became difficult. Some instruments score frailty in a continuous scale ranging from 0 to 1 with no cut-off

points where higher scores indicate the severity of the condition (Cacciatore et al., 2005). Some authors have proposed a two standard deviation cut-off on either side of the median frail score for that population (Mitnitski et al., 2001).

The question that remains is that can one measure then answer the quest of defining the frail population? Most research on frailty tends to either favour the frailty phenotype or the frailty index for their practical translation (Buchman, Boyle, Wilson, Tang, & Bennett, 2007; Ensrud et al., 2007).

Cesari, Gambassi, Abellan van Kan, and Vellas (2014) stress that it is inappropriate to consider both instruments as substitutable as each concept of measure is very different from the other. The two instruments should instead be considered as complementary to one another. The main purpose of the frailty phenotype measure was to detect people at risk of new incident disability by basing on their performance of tasks which will have an impact on the type of fall intervention programme, frequency of hospitalization and healthcare costs. In the latter case of the Frailty 'accumulation of deficit' Index the essence was to assess the burden of frailty to understand and stratify long-term risks for mortality, morbidity and institutionalization (Cesari et al., 2014; Lacas & Rockwood, 2012). The choice of tool to use to measure frailty in a population should be associated to the outcome of interest and the perspective of the stakeholder.

Most frailty assessment tools were derived from existing secondary databases (L. P. Fried et al., 2001; Rockwood et al., 2005) in the developed countries and this provides an avenue for clinicians and policy makers to measure the pre-existing burden of frailty and follow up these individuals over a span of time. However, creating a frailty assessment tool from its roots is a gruelling task. In developing countries that have a dearth in their data management system it would be a feat to create a frailty assessment tool (i.e. Frailty Index) that would encompass all deficits that represent the morbid

health status of an older person. Thankfully there is no stringent rule as to the fixed set of deficits that should be in the tool although there are some guidelines on the items that can be included (Searle, Mitnitski, Gahbauer, Gill, & Rockwood, 2008). It has been reported that estimates of risk with a minimum of 40 risks is acceptable and even shorter versions have been explored (Mitnitski, Graham, Mogilner, & Rockwood, 2002; Rockwood, Mitnitski, Song, Steen, & Skoog, 2006).

2.6 Why measure frailty?

The early identification of frailty is imperative as it may potentially delay or avert several adverse outcomes (Fairhall, Kurrle, et al., 2015). Though there still seems to be a grey area in the definition and measurement of frailty, there is an agreement that identifying the frail elder is worthwhile for the benefit of the individual, family, caregivers and society as a whole. Frailty has been linked with several short term and long term outcomes. Short term adverse events researched to date include falls (Ensrud et al., 2007), outpatient care usage (Fenton, Levine, Mahoney, Heagerty, & Wagner, 2006), hospitalization (Khandelwal et al., 2012), caregiver burden (Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012) and the long term outcomes include health related quality of life (Chang et al., 2012), institutionalization (Abizanda et al., 2014) and death. Economic costs and impacts are also directions that have been explored to assess the impact frail older people have on the healthcare financing needed by the country (Fairhall, Sherrington, et al., 2015) and the investment required to provide respite care to these older people in their homes (Cramm, van Dijk, Lotters, van Exel, & Nieboer, 2011) to allow the carers some personal space.

Clinicians from multidisciplinary fields have explored different manners of quantifying and identifying the various levels of frailty which would assist them in making informed decisions in providing care and managing the older population. Interventions on robust

and pre-frail categories warrant more preventive approaches whereas the frail subgroup deserve the rehabilitative services available in their healthcare setting. These choices need to be justified by them. Frailty assessment has been used by multidisciplinary teams to stratify the risk among the patients and have shown prognostic benefits in the management of these patients (I. C. Wu, Lin, & Hsiung, 2015). Most work on frailty risk assessment was done among the cognitively challenged segment of older people; where frailty is a marker for Alzheimer's disease and dementia, schizophrenia and depression. However, this work has progressed to include non-communicable diseases.

The clinical significance of frailty syndrome in cardiovascular diseases was addressed in a paper by Uchmanowicz et al. (2015) emphasizing the role frailty plays in making therapeutic decisions and risk estimates for cardiovascular patients. Patients who had higher frailty scores had poorer self-care capabilities. This finding is important for physicians during patient's discharge from hospitals, medication compliance and follow-ups. Surgeons were not far behind with using frailty based risk analysis index in conducting preoperative risk assessment in patients undergoing carotid end-arterectomy (Melin et al., 2015). Work today on frailty risk assessment ranges in various cohorts such as outcomes in burn injuries (Romanowski, Barsun, Pamlieri, Greenhalgh, & Sen, 2015), health outcomes in human- immunodeficiency virus (HIV) infected individuals (Akgun et al., 2014) and oncologic outcomes (J. M. Hubbard, Cohen, & Muss, 2014) to name a few.

The public health faculty and services are not left behind in their endeavour highlighting the importance of frailty in an attempt to improve care and delivery of services for the older population. The role of public health specialists has been aptly described by Albert (2004) stating that the speciality draws on the existing knowledge in clinical medicine to promote health beyond the clinic and the doctor-patient encounter. The public health

fraternity also uses epidemiological studies to focus on specific subgroups to provide reasonable secondary preventive goals.

The Survey of Health, Ageing and Retirement in Europe (SHARE) study attempted to measure frailty at a primary care level in the hope of providing personalised community care interventions (R. Romero-Ortuno, 2013). This hope was echoed a priori in a review by Lacas and Rockwood (2012) that identifying frailty in older people allows primary care physicians to make informed recommendations and decisions around preventive and screening interventions thereby, potentially decreasing unnecessary or harmful medical testing. Most of these tools to identify frailty at a primary care level (Bandinelli et al., 2006; Ravaglia et al., 2008; R. Romero-Ortuno, Walsh, Lawlor, & Kenny, 2010) would serve as a complement to the Comprehensive Geriatric Assessment (CGA) which is currently the hallmark of geriatric intervention in most societies. In accordance with the milestones in frailty research some studies have shown the positive effects of exercise (C. K. Liu & Fielding, 2011; Olga Theou et al., 2011), benefits of weight stabilization and protein supplements (de Jong, Chin A Paw, de Groot, Hiddink, & van Staveren, 2000; Paddon-Jones) to improve muscle function and also the role of vitamin D (D. C. Chan et al., 2012) in improving bone function which is an inevitable finding in frailty diagnosis.

Clinical and preventive groups who advocate for the older people ultimately have a duty to educate the policy-makers which requires their concerted effort to provide evidence on why identifying frailty not only benefits certain quarters but a wider platform. This usually involves discussion of the economic benefits that will be obtained either through the cost effectiveness of a particular proposal or savings on expenditure that is currently on-going. The health outcomes studied with regards to frailty has shown an association

with increased demands for health and social needs, in turn increased economic costs (Lally & Crome, 2007).

The International Longevity Centre (ILC, United Kingdom) published a report in 2012 projecting the spending on healthcare to be the largest rise in age-related spending in the next 50 years apart from expenses incurred from spending on public pensions and long term care (Silcock & Sinclair, 2012). An International Monetary Fund (IMF) Working Paper by Heller (2006) explored the preparedness of selected Asian countries in addressing and anticipating challenges of an ageing society. Malaysia has a mixed healthcare financing system today where its public healthcare services are funded through general taxation and the private sector is funded through private medical insurance or out of pocket payments (H. T. Chua & J. C. H. Cheah, 2012). The current medical care system though relatively effective till today may not be sustainable to grapple with the challenge of an ageing population in the future (Heller, 2006). United States and the G7 nations spend a large share of their budget on healthcare (up to 14% of their gross domestic profit: GDP) which alerts us that as we strive to achieve a developed nation status the healthcare costs in Malaysia will increase substantially (Mafauzy, 2000). The 2011 National Health and Morbidity Survey reported that there was a high prevalence of outpatient and inpatient utilization seen among the older people above the age of 60 peaking especially after the age of 75. This increased utilization is most likely attributed to the high prevalence of non-communicable disease such as diabetes, hypertension and hypercholesterolemia among the older people (Institute of Public Health & Institute of Health Systems Research, 2012).

A study done by Mohamed Zaki and Hairi (2014) found that chronic pain which afflicted 15.2 percent of the Malaysian older people was associated with increased frequency of hospitalization. The government has to consider appropriate and

sustainable measures to curb these anticipated costs that can be incurred knowing fully that healthcare and social costs due to ageing issues can cause a strain on the country healthcare expenditure. Hence actions to screen, diagnose and prevent age-related disorders in the community would enable the older people to be less dependent and in turn reduce expenses related to curative services for the older people.

Older people care institutions are mushrooming rapidly to meet the increased demands of the ageing population in many countries. A study in Brazil found that the decision to institutionalize older people was predominant in older age groups (more and equal to 80 years of age), without a spouse or companion, with no formal schooling or with functional disability (Del Duca, Silva, Thumé, Santos, & Hallal, 2012). Among 766 Japanese older people, incontinence among men and visual disturbances among women were predictors for institutionalization (Matsumoto & Inoue, 2007). A systematic review done by Luppa et al. (2010) concluded that the predictors for institutionalization are based on underlying cognitive or functional disability, and associated with those with lack of social support and assistance in daily living. It is evident that the constant predictors of institutionalizing the old are the urgent need to provide care when the immediate family is unable to provide it themselves. This could either be due to the inability of the working women (who have always been held responsible for care giving) to reconcile their careers and family burdens or the inability to cope with stress of providing for them (Kurasawa et al., 2012).

The financial perspective with increased healthcare burden among the old is another common factor that sways the caregiver toward neglect on care-giving (Lai, 2012). Frailty is ultimately seen in some form in every older individual with the difference probably in the age of onset and this phenomenon is closely related to physical or cognitive disability. Identifying this subgroup of older people will provide some insight

as to the status of the older people and serve as an indicator for the care-giving environment at home.

The stakeholder that is sometimes forgotten in this whole process are the older person themselves. Over the last two decades, gerontologists have been working on a concept called 'successful ageing' proposed by Rowe and Khans' ageing model which has three components in its definition; low probability of disease and disease-related disability, high cognitive and physical function capacity and active engagement in life (Rowe & Kahn, 1997). While all three components of this model has active on-going research and carefully laid policy framework, the fundamental essence of this model are the older persons themselves having a vested interest in their health and well-being. Understanding the biology of ageing and their own role in averting ill-health, disability, ensuring optimum cognitive function, and being socially active are essential paths that lead to better assurance of health. While defining frailty may assist policy makers and clinicians provide better avenues, platforms and interventions to ease the ageing process, knowing the dynamics that go into the transition of frailty may provide awareness among the old to take responsibility themselves to deter the transitional process further. Knowledge on the demands that ageing and age-related disorders take and the social, financial and emotional toll it may exert in the future may guide the baby-boomer generation to gain resilience and take life-changing measures in time.

The justification of measuring frailty is usually determined by the stakeholder who measures it. We have several groups of people who have different perspectives when they measure frailty levels in a population; for instance the clinical geriatricians may be more involved with risks stratification of these older people to enable better clinical management, the public health perspective would be more skewed towards preventive approaches in the future to delay the transition between from robust to frail. The

government and authoritative figures of the nation would need the economic perspective factored in to ensure the sustainability of these interventions or plans undertaken and to channel the resources effectively and in a justified manner. The older people and their families too have an important stand in this issue that is to understand the ageing process and to take informed and adequate measures to prepare themselves to age independently and peacefully.

The real challenges in caring for the ageing population was aptly described as a) having a long-term and sustainable payment or insurance scheme, b) ensuring the health and independence of the older people with advancements in curative care, c) accessibility of community services and behavioural changes in the society, and d) cultural adaptations to coalesce aged into community (Knickman & Snell, 2002). These issues are evident in most societies that grapple with ageing issues and addressing them gradually would be a positive step toward obtaining concrete changes in the society.

2.7 Summary

Despite the inconsistencies in defining frailty and a gold standard tool to measure the condition, frailty is unanimously agreed upon as a geriatric syndrome that deserves urgent attention. Focus on geriatric health today has been confined to specific disease burdens such as hypertension, diabetes, cancer and sense organ disease which are usually diagnosed during a visit to the doctor for a new symptom or sign experienced by the older people.

People over the age of 60 instead have a number of conditions and want to be treated as single individuals with person-centred care rather than a collection of diseases to be managed. M. T. Puts et al. (2012) explained that “In the geriatric medicine setting, frailty is not considered to be the endpoint of the continuum of fit to completely

dependent; rather it represents a state where an individual is independent but at high risk of developing disability". This reinforces the need to screen for frailty in any older person as this risk is constantly present and early detection can give a new lease on their life.

The types of work done on frailty range widely as shown in this review but what remains consistent is that the condition of frailty has outcomes that have profound impact on the lives of the older people, the wellbeing of the family or caregiver and the nation. We know from the review above that the condition of being frail has been associated with increased co-morbidities, a combination of ailments involving several end organs, increased predisposition to falls and a high risk of mortality. These outcomes indicate that this would in-turn have an impact on increased utilization of healthcare services and automatically driving up healthcare costs. The older people who are economically disadvantaged due to depleted savings and less active source of income will have to turn to their dependents or caregivers for support and financial aid. The burden of care does not limit to only the provision of assistance of daily living for these frail older people but also in terms of time, money and patience. This is an issue of concern as most caregivers might be unable to cope with the burden of care and resort to institutionalization, abandonment or abuse. Hence, by determining the level of frailty in an individual we can prevent or delay institutionalization, hospitalization, morbidity and mortality by taking appropriate preventive measures before they hit the 'frail' mark. The older people who are already diagnosed as frail can be given due undivided focus to delay their disease progression and support them with the care they deserve.

We know that recurrent admissions and long stays in the hospitals are seen among the frail older people. During the admissions the symptom or sign that required the intensive management is the focus and once that is normalized, there is a plan for

discharge. However, the many other domains afflicting an older person such as social support and daily care is often overlooked. If there is no continuity of care available at the home or the community level, the caregiver or the older people tend to delay discharge due to the apprehension of future care at home. This drives up the cost of health due to unwarranted long stays and admissions. If the older people are educated effectively to understand their long term condition, and given the support system to live independently they are less likely to burden the healthcare system. Caregivers who are financially and physically unable to cope with the various needs of an older person will resort to the desire to institutionalize them. This will overload the institutional and nursing homes and drive up cost of older people care for the country especially in Malaysia. This way the nation also stands to benefit from the screening of frailty by preventing the issues above.

We do know that frailty has its unique profile of disease evolution and outcomes. This requires a skilled set of professionals, allied health and caregivers, and a coordinated system in place. To get this right, it is essential to look across at the policies and resources in the health system currently in place and ensure the right skills and services are available to accommodate and manage the frail older people in a holistic manner. In order to build a meaningful future for our ageing population, getting services right for the right geriatric condition is important to avoid silos in their provision of care.

CHAPTER 3 PUBLIC POLICIES ON OLDER PEOPLE CARE IN MALAYSIA

3.1 Introduction

The ageing population in Malaysia has its own unique profile and needs and the government has to respond to these needs effectively. The spectrum of issues that affect the older people are not only limited to health issues, but also concerns social security, financial security, aged care and support, institutionalization, caregiver burden, community support and rehabilitative avenues just to name a few. However, for the purpose of this thesis, the focus is on public policies on health and healthcare issues of the older people.

The challenges and demands on the public and private health sector, non-governmental organizations for the older people and the community will take a heavy toll if careful and coordinated planning is not taken early (Kielstra, 2009). It is fundamental that the policy that is drafted for health and social needs focus on the current needs of the population at hand rather than only deal with yesterdays' challenges (Ham, Dixon, & Brooke, 2012).

Policy planning and designing for the older people community is complex as it has to consider all physical, mental, nutritional and social domains to provide a holistic care concept. However, most policies are born out of the urgent need to answer the pressures of vocal groups which champion different elder cause and thus are likely to result in disaggregated implementation of the intended objectives. It has been stressed by Bowling (2005) that researchers and policy makers are not on the same page when they define and measure health and a balance between these two forces are pertinent to developing a quality public policy for older people.

This review aimed at understanding the existing public policies for the older people in Malaysia will examine the flow of these policies from planning to implementation, identifying gaps and issues that were faced in this path, analysing the various programmes that are being conducted for the older people in Malaysia under the health system, identifying the various stakeholders who have a pivotal role in older people health apart from the Ministry of Health and recommending policies for early identification of frailty to ensure appropriate management of Malaysian older people.

The methodology used to obtain the information for this review is described in section 3.2. Section 3.3 gives an insight on the initial development of the public policies for the older people in Malaysia. Then Sections 3.4 gives an overview of the different policies for the older people in Malaysia. Sections 3.5 and 3.6 give an understanding on how these policies were planned, developed and implemented at three different levels of care; primary, secondary and tertiary levels. In Section 3.7 policy evaluation is done to see if the activities implemented achieved the intended outcomes. The district of Johor Bahru as described earlier (in Chapter 1, Section 1.2) due to its unique elder profile is evaluated for its elder wellness programmes. Section 3.8 summarizes the findings of this review.

3.2 Methodology

3.2.1 Study design

The study design for the older people policy review in Malaysia was by data triangulation of multiple sources of information to provide a robust and comprehensive understanding of issues (Flick, 2004). There were three main sources of information which were used for this review; review of document and datasets, key informant interviews of stakeholders involved in the policy process from designing to implementation and formal correspondence with various health personnel who were directly or indirectly involved in ensuring older people health at the primary care level.

To date, six documents have been released by the government concerning health and well-being of the older people in Malaysia. Hence, they were chosen for this review. The documents that contributed to this report were The National Policy for Older Persons 1995, Action Plan for Elderly Wellness Programme 1997, National Elderly Policy 2011, National Health Policy for Older Persons 2008, Action Plan for Elderly Wellness Services 2008 and Guidelines for Implementation of Elderly Health Services at the District, Clinic and Community Level 2008 (2nd Edition).

A search from the historical archives of older people's health from the Ministry of Health (MoH) and Ministry of National Unity and Social Development was done. A visit to the parliament to peruse through the Parliamentary Hansard from 1990 to 2013 which spans the period between policies planning for older people care to implementation complemented the findings of the document review. Visits to the district level health clinics having Elderly Wellness Clinics and Elderly Wellness Clubs in Johor Bahru were done to collect and analyse datasets on attendance and programmes to obtain a realistic perspective of the care of the older people we have today.

3.2.2 Key informant interviews

The implementation of the older people health services starts from the Ministry of Health (MoH) headed by the Senior Principal Assistant Director (Family Health), Family Health Development Division in charge of older people health whose responsibilities include guiding, planning and monitoring all health activities and programmes pertaining to older people health in Malaysia.[2] Below that would be the respective State Health Directors who act as advisors to the District Health Officers under their jurisdiction. Each district under the leadership of the District Health Officer forms its own committee to plan, coordinate, monitor and evaluate resources, programmes and activities for the older people in that district.

For the purpose of this review, several key informants were chosen and interviewed to gather the required information. A face to face interview was conducted at the Ministry of Health headquarters with Dr Mohamad Bin Salleh from Putrajaya, who is the current Senior Principal Assistant Director (Family Health), Family Health Development Division in charge of older people health to obtain a federal level perspective for older people health policies and programmes.

[2] The Ministry of Health (MoH) established under the Malaysian government is led by the Minister of Health. The administrative leader for the health system is the Director General of Health. The organization of the Ministry is further divided into six main sectors; medical, public health, research and technical support, oral health, pharmaceutical services, food safety and quality divisions. Under the public health division the family health division is responsible for maternal and child health and older people health. From the federal level, the management of each stste comes under the respective state health department which manages the hospitals in the state and the distric health offices belonging to that state. The district health office is responsible for the health and well-being of all persons residing in that specific district.

The Johor state head for Primer division who was given the charge of older people health, Dr Faridah Binti Hj. Ali was also interviewed to understand the responsibilities and activities in the state of Johor and the district of Johor Bahru. The Johor Bahru District Health Officer, Dr Badrul Hisham bin Abd. Samad was interviewed to get an overview on his stand on older people's health in Johor Bahru. The doctors and nurses who have been involved in Elderly Health Clinics and Elderly Wellness Clubs in three primary care clinics in Johor Bahru were interviewed to understand the issues and challenges at the implementation phase of the policy. Dr Philip Poi, a senior geriatrician from the Department of Geriatric Medicine, University Malaya Medical Centre was interviewed as a proxy for the policy planning stakeholders as he was involved in the policy planning process in the early 90s in Malaysia.

3.2.3 Data analysis

The interviews were transcribed and data triangulation method was used to ensure there was validity in the data collected. Sources of triangulation were personal interviews, written documentations such as the Parliamentary Hansard, original policies and guidelines, datasets on older people health services available in the district of Johor Bahru, books, and journals published by academic researchers.

3.3 Initial impetus for development of public policies for older people care in Malaysia

The first World Health Assembly on Ageing was held in 1982 and this started the global trend of focusing on older people health issues which were beginning to increase rapidly in most societies. However, it was never the interest of the developing nations in the world at that time to steer in that direction while they were still striving to manage their burden of communicable diseases. Remarkably, just in two decades, efforts in ageing issues have begun to gain importance in these developing countries. An issue which had sustained the interest of the developed nation has now got the attention of developing countries.

The idea behind the 1982 World Assembly on Ageing was to launch an international platform aimed at guaranteeing social and economic security to older persons as well as opportunities to contribute to national development (United Nations, 1983). This International Plan of Action was conceived to enable societies to respond more fully to the needs of the older persons and the socio-economic implications connected with ageing. This platform was formed in accordance with the global trends in increasing life spans that were observed.

The participating countries took the International Year for the Older Persons which was launched in 1999 as an opportunity to adopt new policies or review their existing policies (Economic and Social Commision for Asia and the Pacific, 2000). Most countries in Asia and the Pacific welcomed the idea of the International Year for the Older Persons by having focal points and mechanisms at national and local levels to generate awareness on issues related to ageing, integrate older persons into the mainstream development and promote multigenerational relationships (Collard et al.,

2012). The report also highlighted the fact that some countries like Thailand, Vietnam, Republic of Korea, Indonesia and Malaysia addressed ageing issues as a joint collaboration between the government and the non-governmental organizations (NGOs). The distinctive efforts were in terms of joint sponsorship, shared resources and mobilizing community support. Since 1999, the United Nations General Assembly celebrates the older people by raising awareness on issues surrounding the older people and acknowledging the contributions that older people make to society (United Nations, 2012).

Malaysia's total population in 1990 was approximately 21 million and only 5.7 percent of the population were above the age of 60 (Mafauzy, 2000). Although the growing rate of the older population in Malaysia was much slower than some countries globally, the Malaysian government took the increasing ratio into consideration and to came up with a policy for the older people called the 'National Policy for Older Persons' in 1995 (Ministry of Health, 2013). In line with that policy the National Advisory and Consultative Council for Older Persons was set up and this council established a Plan of Action for Older Persons. In 1992, Malaysia declared October 1st as 'National Senior Citizens Day' to commemorate the same day declared by United Nations as 'International Day of Senior Citizens' (Resolution No.45/106) (Department of Social Welfare Malaysia, 2013).

3.4 Overview of public policies for the older people in Malaysia

Most governments in the world usually develop policies ad hoc to troubleshoot a rising or occurring problem in their nation. Similarly, in response to the dramatic increase in longevity, national policies on ageing have been developed around the world mostly failing to address the needs, reach acceptable standards and provide adequate social

support for the older people (United Nations, 2009). Nee (2006) reported that prior to the first national policy for the older people which was developed in 1995, health and social concerns for the older people in Malaysia came under the National Social Welfare Policy (1990). This policy was drafted solely to address the needs of the older people where families played the primary role in continuity of care. Health concerns and issues for the older people in the 1990s were based on the sole virtue of the Confucian philosophy of 'filial piety' and no sector took full responsibility to cater for the needs of the older people. Government aid mainly came from the welfare department in Malaysia in the form financial assistance, assistance for artificial equipment and institutional services.

However, after five years the Department of Social Welfare under the Ministry of National Unity and Social Development decided that the nation should have a more holistic and comprehensive plan for the older people. Following this, Malaysia saw the birth of The National Policy for Older Persons in 1995. This was declared as the official policy for the older people in Malaysia during the celebrations of the first 'National Senior Citizens Day' on 29th October 1995. The National Policy for the Older Persons had a five domain strategy (Figure 3.1) to realize their mission statement which was 'To ensure the social status, dignity and well-being of older persons as members of the family, society and nation by enabling them to optimise their self-potential, have access to all opportunities and have provision for care and protection.'

Figure 3.1 Strategies for the National Policy for Older Persons Source: (Department of Social Welfare, Malaysia 1995)

The first domain 'respect and self-worth' was to enable the older people to receive fair and just treatment, equal opportunities to realize their optimum potential without being subjected to oppression and abuse. The second domain is 'self – reliance' where the needs of the older people are met through a steady source of income, family and societal support. The third domain 'participation' stresses ability for the older person to play an active role in society and contribute voluntarily to the nation. The fourth domain 'care and protection' includes provision of an optimum healthcare system, institutional services, social and legal services to advance their autonomous rights and to have a comprehensive social security system to ensure a stable income and welfare for the older people. The final domain 'research and development' is highly essential in this strategic planning to gather information, to identify and coordinate the needs of the older people.

The action plan for this policy was formulated with inter-sectorial input consisting of 34 members led by the National Elderly Consultation and Advisory Council which was

formed on 22nd May 1996. The Social Welfare Department under the Ministry of Women, Family and Community Development which is the secretariat for this council was identified as the agency responsible for the coordination and implementation of these strategies. Following the National Policy for Older Persons in 1995, the government developed the Action Plan for Elderly Wellness Programme in 1997 through the Ministry of Health as healthcare was deemed a priority concern for the older people. On September 1999, the Action plan for The National Policy for Older Persons was released by the Ministry of Women, Family and Community Development which included all other priorities for older people such as social and recreation, education and spirituality, employment opportunities, housing and environment and research and development.

The National Policy for Older Persons 1995 was formulated to cover all aspects of need and care for older people, healthcare being one of its priority efforts. The other projects were to focus on education which involved both generations, employment opportunities so that they may still contribute to national development and be socially self-reliant, encouragement of participation in community activities, provision of recreational facilities, user-friendly transport system to commute independently, support system of the family by provision of incentives, suitable housing, a comprehensive social security system , increasing the role of media to create awareness and conducting more research to obtain evidence based information.

In 2008, under the new government led by the then Prime Minister, Tun Abdullah bin Haji Ahmad Badawi a relook into the National Policy for Older Persons (1995) was done and a new policy called 'The National Elderly Policy' was drafted and released in 2008. To complement this policy the Action Plan for National Elderly Policy (2011) and the National Health Policy for Older Persons (2008) was redrafted to meet the older

people needs at the time. Figure 3.2 depicts the chronology of public policies for the older people in Malaysia.

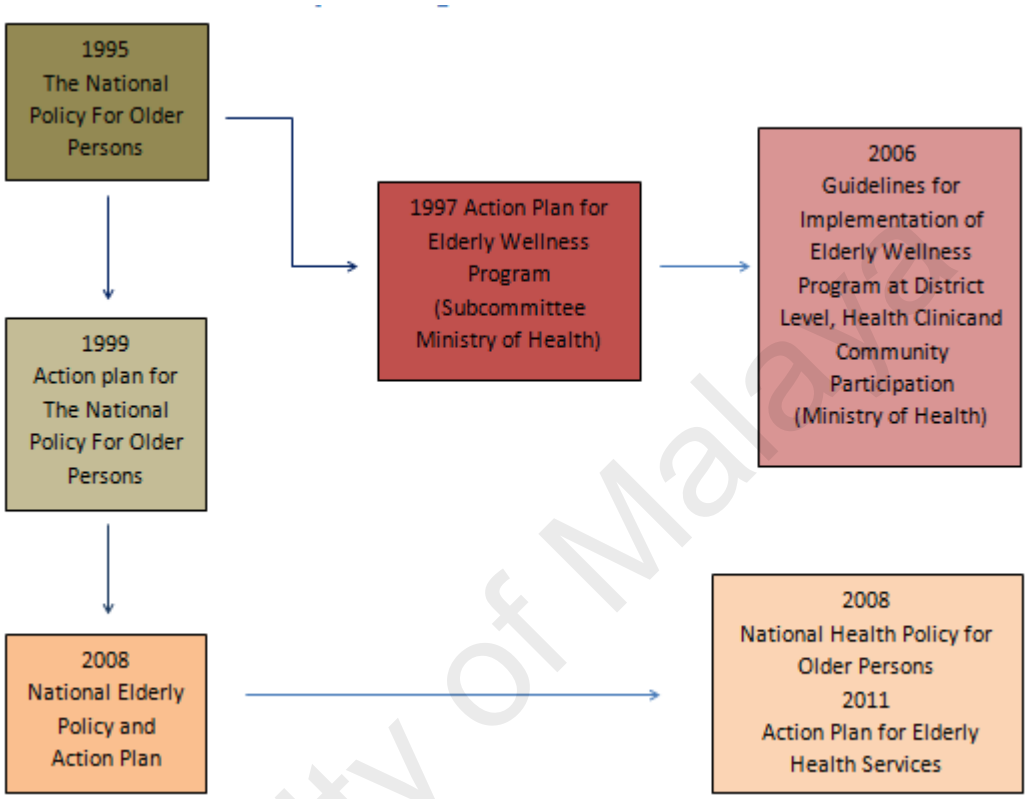

Figure 3.2 Chronology of Public Policies for Older people in Malaysia

3.5 Development of policy for the older people

In designing a policy it is vital that to have a profound impact on health outcomes it should be evidence based. R.C. Brownson, J.F. Chiriqui, and K.A. Stamatakis (2009) described three main domains to focus on when formulating a policy; the process, content and outcomes.

There is a large gap between what is effective and what is implemented or enforced. This is due to the barriers faced by policy makers to develop evidence based policies such as lack of skill of understanding the issue at hand, poor value for preventive

activities in the budget likely due to doubts in long term outcomes and power of vested interest in non-urgent issues (Brownson, Newschaffer, & Ali-Abarghoui, 1997). Researchers and academicians who are working on evidence based perspectives are also not included in the policy making process. Professor Phillip Poi, a geriatrician in University Malaya explained, "*When these policies for older people were proposed and developed, it was never from the evidenced based needs of the older people. Research on older people were few and usually the academia does not have a role to play in this policy making process in the government.*"

Similarly, in Malaysia, the National Health Policy for Older Persons and The Action Plan for Elderly Health Services did not arise out of one single model or theory. Due to the failure in accessing the parliamentary transcript or policy proposal meeting the exact climate in which the policy was conceived is difficult to understand. However, it is quite evident that in 1995, when the first National Policy for Older Persons was implemented, Malaysia did not face the burden of an ageing nation which may have resulted in policy objectives which were not targeted to address issues afflicting the older people at that time.

Foreseeing a similar future of other developed countries for the Malaysian older people, the Ministry of National Unity and Social Development decided to have a more effective, comprehensive policy for older persons. This policy was formulated within the context of existing international and national actions such as The Vienna International Plan of Action on Ageing 1982 and World Health Organization Health of the Elderly Report 1989 (Ministry of Health, 1997; Ministry of National Unity and Social Development, 1995).

The design of the health policies usually reflects the political climate of the country. This viewpoint has been eloquently described by Judge (2008) on how various political systems can influence the tone of the policy and health outcomes. The article describes that it is impossible to understand some of the health inequalities in policy in England without acknowledging the ideological differences between two governments which are the Thatcher/Major and Blair/Brown in the past two decades. He also explains that even within one party tradition there are sometimes different Ministers trying to put their personal imprint on policy which complicates it further.

The 2008 National Health Policy for Older Persons was conceived with multi sectorial input and collaboration to revise the a priori existing policy. The rationale of the policy was that health of older persons is unique with specific needs hence the health service planning should be parallel to those needs. The other aspect of the policy is the financial resources economics of the aged which depletes as soon as they retire and being healthy will help offset medical and social care costs that can burden them.

The action plan proposed to execute the objectives of the policy was rather holistic in nature. It was the result of seven think tank groups which reanalysed the earlier action plan proposed in 1997 and revised according to the needs of the 21st century older people. The main strategies that were focused upon were:-

a) Health Promotion
b) Provision of a Continuum of Comprehensive Health Care Services
c) Human Resource Planning and Development
d) Information System
e) Research and Development

f) Interagency and Intersectoral Collaboration; and

g) Legislation

3.6 Implementation of policy on the older people

A health policy is usually implemented out of four key considerations as proposed by K. Lee and Mills (1982) which are an urgent need to contain escalating costs, various political ideologies of the existing political parties, moral or ethical values or just as a commitment from the powerful and ruling group.

In Malaysia, the National Health Policy for Older Persons may have been part of the need to raise the quality and standard of health for all ages to be at par internationally. Due to the competing demand on the available and finite resources, most of the decisions made are based on the immediate needs such as medical screening programmes and treatment for common non-communicable diseases like hypertension and diabetes, screening for vision and hearing disabilities, conducting recreational and social activities at elderly health clubs, and health education and information through talks and pamphlets. Most of these activities are carried out at the primary care level and with a referral for complicated cases to the secondary or tertiary centres to general physicians, geriatricians if available, or the specific specialties such as psychiatrist, ophthalmologist and otorhinolaryngologists.

In 2013, only nine government hospitals had a geriatric unit with 16 geriatricians across Malaysia (Ministry of Health, 2013). The Malaysian Country Report for the 11th Asean and Japan High Level Officials Meeting on Caring Societies in Tokyo, Japan also highlighted that training was also given to primary care staff to handle health issues for the older people to buffer the dearth of geriatricians in the country.

Another pertinent issue here is that older people health problems have to be viewed as an issue of interest for the success of this policy. A comparative study done on nursing students found that only 10 percent of the third year nursing students and none of the first year students were keen on nursing an older person (Wan & Poi, 1997). The dearth of geriatricians in Malaysia and the lack of primary care physicians trained in geriatrics remain a barrier to provide seamless care for the older people in Malaysia (Poi, Forsyth, & Chan, 2004). The authors add that appropriate and thorough assessment of older people requires time and with the time-constraints faced by private general practitioners and primary care physicians, further exacerbates the complexity of the situation. The programmes and activities that were launched under the National Health Policy for Older Persons will not be sustainable if adequate resources in terms of money and infrastructure and trained human capital are not available to ensure in the continuity of these services.

The health policy in Malaysia for older people is a stem of the main National Policy and Action Plan for Elderly 2008. The technical committee spearheaded by the Policy Planning Division of the Ministry of Women, Family and Community Development is the lifeline to effective implementation and through coordinated action of all the subcommittees involved. The technical committee is responsible to plan annual activities, coordinate state level planning and development and present sufficient evidence for sustainable funding. Below is the organization structure for the Elderly Policy in Malaysia from various sectors (Figure 3.3).

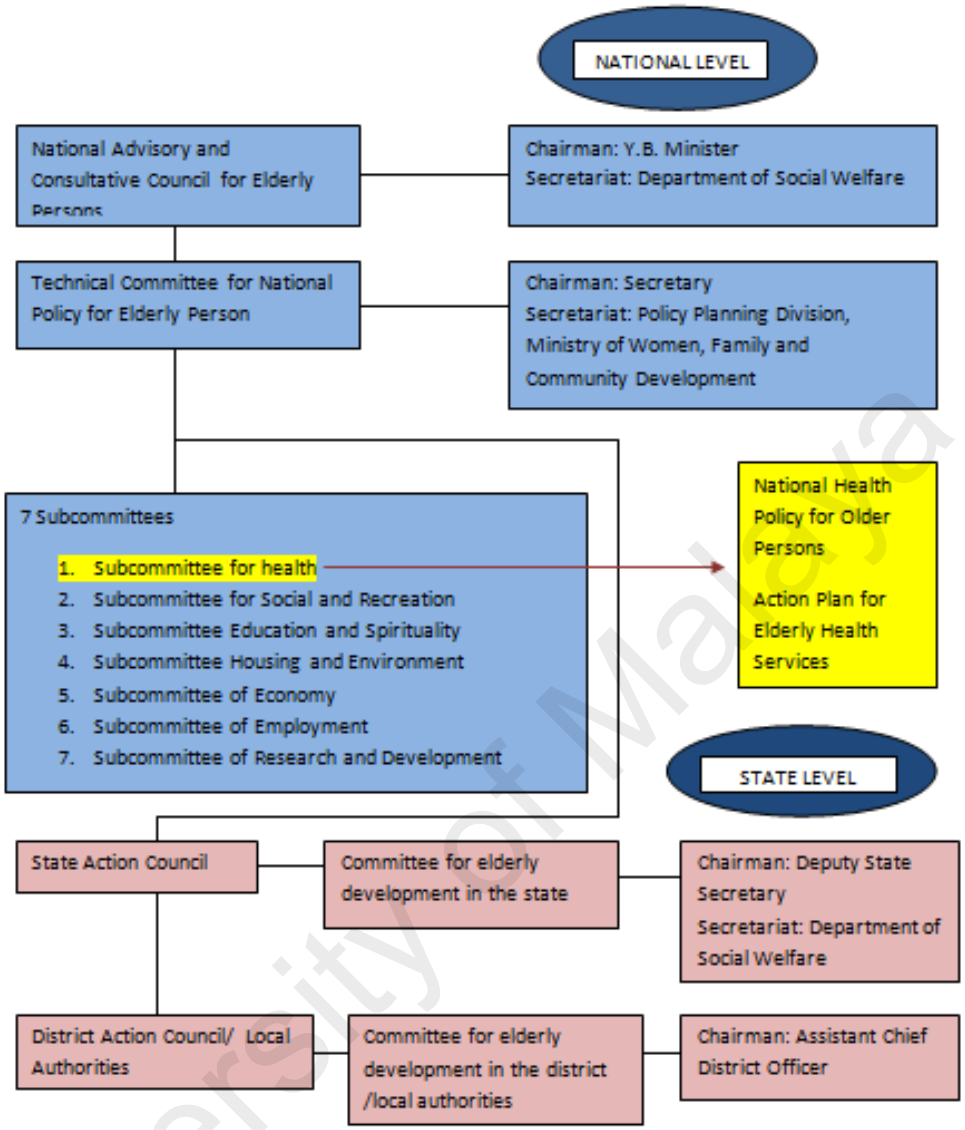

Figure 3.3 Organization Structure for Elderly Policy in Malaysia Source: National Health Policy for Older Persons 2008

The implementation of the National Health Policy for Older Persons (2008) was through the Action Plan for Elderly Health Services (2008) and Guidelines formulated by the Family Health Division (2006 revised) but the manner it has to be articulated at the state or district level should be standardized which can lead to its discontinuity in many of these districts.

During the interview, Dr Mohamad Bin Salleh, Senior Principal Assistant Director (Family Health), Family Health Development Division stressed that, "*The state*

department has to play a very strong and supportive role to coordinate all the activities being executed at the district level and to obtain a continuous feedback on its progress. The monitoring and evaluation of these activities has to be done incrementally to improve the quality of their outcomes."

The implementation of the National Health Policy for Older Persons has been subdivided into two main components – the primary care level and the secondary/tertiary care level. This division was done to provide targeted services for the older people as the activities required at different levels were specific. The objectives targeted at the primary level were:-

a) To plan, coordinate, execute, monitor and evaluate older people health services.
b) To plan manpower, resources, infrastructure and budget for the services.
c) To provide continuity of care at all levels.
d) To improve the health and wellbeing of the older people.

At the secondary and tertiary levels the strategy was to strengthen the medical, psychological, dental, rehabilitative and palliative care provided currently, expand the current geriatric services to psycho geriatric services and improve the knowledge and skill of all health personnel involved in geriatric care.

The various resources that were planned for allocation in terms of finances, manpower, facilities equipment and training at the primary, secondary and tertiary levels are described in Tables 3.1 and 3.2. For the primary care level, a five year plan (2008-2013) was done allocating approximately RM6.5 million for manpower and training resources, RM4 million per year for extra buildings in clinics to cater for the older people, a little above a million per year for physiotherapy and rehabilitative equipment, and another million per year for training of allied health personnel and international training.

Similarly, for the same five years an approximate sum of RM 2 million per year was allocated for manpower, training, infrastructure, age friendly infrastructure, equipment and multidisciplinary training at hospitals.

Dr Mohamad Bin Salleh also added, "*Though there is a structured manner in which the older people wellness programmes are designed most of the states and district could not implement them as recommended by guidelines. So, for now the districts that have older people wellness programmes are monitored for their effectiveness and other districts are encouraged to start up the programme.*" He continued to say, "Though *the budget allocations to run the programmes were planned, the money could not be allocated from the budget. The final sum was not sufficient to launch the programmes on a large scale*."

Table 3.1 Resources that were allocated for Primary Care Level Activities (Ministry of Health, 2008)

INPUT (PRIMARY CARE LEVEL)		
Time Duration	2008-2013	5 years
Resources	Manpower Financial – Facilities, Equipment, Training	Approximately RM 6.5 million
Collaboration	Ministry of Health, Welfare, NGO, clinical disciplines, primary care, national institutes,	Home volunteer services Advocacy for NGOs and volunteers to aid at institutions Visits to institutions to create a network Health Information Portal – Knowledge Management and Statistical Data Centre Produce annual reports on older people health services
Facilities	Infrastructure – Extra buildings in clinics	RM 4 million /year
Equipment	Rehabilitative, Physiotherapy, Screening,	RM 1.125 million/ year
Training	Training Module Physiotherapy Training Multidisciplinary Training Practice Training International Training	RM300000 RM 480000/year RM 24000/ year RM 70000/year RM 105-RM115/year

Table 3.2 Resources that were allocated for Secondary and Tertiary Activities (Ministry of Health, 2008)

INPUT (SECONDARY & TERTIARY CARE LEVEL)		
Time Duration	2008-2013	5 years
Resources	Manpower Financial – Facilities,, Training	Approximately RM840000/per year
Collaboration	MOH, Welfare, NGO, clinical disciplines, primary care, national institutes,	Training institutes Universities Information and Technology Units Telehealth services Health education unit Health promotion unit
Facilities	Age friendly infrastructure Equipment for ward Occupational therapy equipment in hospital Physiotherapy equipment in hospital	RM 200,000 /year/hospital RM 200,000/year/hospital RM200,000/year/hospital RM200,000/year/hospital

There are several other stakeholders for the older people who participate in the welfare and responsibilities for caring for the older people in Malaysia. The mainstay of older people services in this country is provided by the Department of Social Welfare Malaysia, under the Ministry of Women, Family and Community Development. The secretariat is responsible to regulate, render assistance and provide any form of support for the older people and to achieve the various objectives of the policies under their wing.

The programs that come under the Welfare that involve the senior citizens are KAR1SMA founded to transform the existing welfare services to a marginalized population, provision of financial assistance, institutionalized services, day-care centres and visiting and home help services, Senior Citizens' Activity Centre, a walk in day care centre which prioritizes the older people above the age of 56 who are fit and independent, Senior Citizens' Care Unit, an initiative under the collaboration of Peninsular Malaysia Welfare Council, a voluntary body and the Department of Social Welfare to provide transport services to the hospital or clinics for treatment and continuity of care. This is only applicable for the older people without families and who live alone, Senior Citizens' and Family Institutions which are regular welfare homes and also homes for the destitute.

The National Association of Senior Citizens of Malaysia (NASCOM) is a non-governmental organization which functions as a voice for the senior citizens of Malaysia, to advocate the development of sound and favourable policies that will enhance the future wellbeing.

The Institute of Gerontology Malaysia in its first international collaboration with the United Nations Population Fund is currently undertaking projects in areas with high number of older persons to understand and study the possibility of empowerment and

greater participation of the older people in their lives to promote active and productive aging in Malaysia (United Nations Population Fund Malaysia, 2005). The diligent efforts of geriatricians in Malaysia have given a new lease in life to our many senior citizens in Malaysia.

In this country with our unique two tier health system, we have to cater to our older people in the public and private sectors. However, the numbers of geriatrician are far below our needs. Services provided by these clinics include fall clinics, memory clinics, anti-aging and regenerative medicines and terminal illness care. The issue at hand here is while these services are available in Malaysia and are currently blooming, the numbers of older people who enjoy these services are few due to insufficient geriatricians and geriatric training among primary care practitioners (Poi et al., 2004).

3.6.1 Implementation of wellness services for the older people in Johor Bahru

Most of the state and district health offices which have ventured into elder health use the 'Guidelines for Implementing Elderly Wellness Services in the District, Health Clinic and Community Involvement' report published by the Ministry of Health as a reference to start their programmes.

Implementation of wellness services for the older people in Johor has been done gradually according to Dr Faridah Binti Hj. Ali, the state head for the Primer Division. In the Johor state level, health of older persons came under the primer division as there was no specific older people unit and there was inadequate staffing under the family health unit. Dr Faridah Binti Hj. Ali mentioned that, "*Most of the programmes intended for older people come as directives or circulars from the Ministry and based on the resources we have we decide how it can best be implemented at various districts. We do encourage starting programmes but these directives do not come with much financial provision, so we try to adopt the programmes into current programmes that are already*

in place." She also added that, "*the decisions on implementation at the district level is made by the respective District Health Office as reports that need to be returned to the Ministry directly comes from the individual district.*" This shows that the implementation of the older people wellness programmes are not monitored at the state level.

An interview with Dr Badrul Hisham bin Abd Samad, the Johor Bahru District Health Officer on the 5th July 2015 gave some insight on issues pertaining to programmes for the older people in Johor Bahru. According to him, "*Elder programmes started in the early 2000 focusing on rehabilitative and end-of-life care, and then there was encouragement to start of elderly wellness clinics and clubs at the district level initiated by the State Health Office. However, a specific budget was not allocated for such programmes which made it rather difficult to sustain a programme*." Currently older people clinics are conducted on specific days and restricted to only one health clinic in Johor Bahru. Elderly Wellness Club initiation was solely under the discretion of the medical officer or family medicine specialist in charge of the respective health clinic. If they deemed it suitable and had adequate resources to start a club, they were encouraged to do so. He also added that "*There is no support and planning from the Ministry hence most of the activities are almost non-existent for older people or even those functioning are not monitored effectively by the Ministry*.

Table 3.3 highlights the implementation of elder wellness activities in the district of Johor Bahru. Out of the 12 health clinics in Johor Bahru only one clinic started off an Elderly Wellness Clinic and is able to still sustain it on a weekly basis (Tuesday evenings). During a formal correspondence with Dr Vidya Vijayan, Medical Officer in charge of older people health on the 15th July 2015, it was understood that Mahmoodiah Outpatient Clinic started the Elderly Wellness Clinic in 2009. According to Dr Vidya,

despite the drive to increase the numbers screened in the clinic, there was poor response from the older people as they had too many appointments to meet (since non-communicable disease was still not part of the older people wellness clinic) and most of the older people defaulted their appointments. Another problem raised by her was that currently the screening form was very specific and once referral is done for confirmatory diagnosis to the respective specialities the patient is lost from the primary care system. During the interview, she said that, "*The patient also tends to default with so many appointments for diagnosis due to lack of geriatricians in Johor Bahru and due to the high turnover and shortage of staff, the older people wellness clinic tend to fail*."

There are currently three health clinics maintaining an Elderly Wellness Club but from the data in Table 3.3 below there is a decrease in attendance or recruitment of new members into the club over the years. Table 3.3 shows attendance and activities at the Tampoi Elderly Wellness Club increasing as the years have passed with large numbers of attendees. This is one of the most successful clubs in the district of Johor Bahru. According to Puan Jasbeer Kaur a/p Santosh Singh, staff nurse in charge of the Elderly Wellness Club at Tampoi Health Clinic, this club is only able to sustain and have many activities because the club is fully managed by the older people committee members with the assistance and support from the health clinic. Most of the members plan and fund their own activities and function like a non-governmental organization (NGO).

During data collection, discussion on issues faced on implementing and maintaining older people wellness activities was obtained from the respective medical officers and specialist in charge of the health clinics and is summarized in Table 3.4 below. The common issues that arose were inadequate resource, staff, and training on older people health. Dr Badrul Hisham bin Abdul Samad explained that since there was also no monitoring on achievements at the district, state or national level for these activities, the

health personnel tend to prioritize other health issues which need to meet performance indicators set by the Ministry.

There have been several activities implemented at the grass root level as per the schema but this is evidently not sustainable as the surrounding infrastructure does not complement these facilities provided citing wellness clinics as an example, there have been many district clinics equipped with wellness clinics for the older people but it was incorporated as part of the running clinic schedule and no increment in manpower. The fact that the client required adequate family and societal support further dented the industrious idea. The involvement from the Ministry to ensure the success of this program has also decreased. Most of the health personnel interviewed find that resource allocation in terms of money and human capital is an important perspective that has to be looked into prior to the initiation of programmes as this will ensure the sustainability of that programme.

The implementation of older people activities in Johor Bahru though present is still not optimum and does not cater to the needs of geriatric issues today. This is most likely caused by the low importance given to older people health and well-being issues at the policy making level. The final outcome of the intended programme shows that the care provided at the clinics is not holistic and the continuity to screening done is not in place. Even health staffs involved in the primary care level older people wellness activities have poor awareness and knowledge on the importance or types of older people health issues. There is an urgent need for reactivation of the National Policy for Older Persons and more sustainable guidelines to be drawn up for the older population.

Table 3.3 Older people wellness activities in the district of Johor Bahru

HEALTH CLINICS IN JOHOR BAHRU	HISTORY AND LAUNCHING OF ELDERLY WELLNESS PROGRAMMES	ELDERLY WELLNESS CLINIC ATTENDANCE (NO. OF PATIENTS FULLY EXAMINED)				ELDERLY WELLNESS CLUB ATTENDANCE				ELDERLY WELLNESS CLUB NEW RECRUITS				NO. OF OLDER PEOPLE ACTIVITIES IN 1 YEAR			
		Jan-Dec 2011	Jan-Dec 2012	Jan-Dec 2013	Jan-Dec 2014	Jan-Dec 2012	Oct–Dec 2013	Jan-Dec 2014	Jan-June 2015	Jan-Dec 2012	Oct-Dec 2013	Jan-Dec 2014	Jan-Jun 2015	Jan-Dec 2012	Jan-Dec 2013	Jan-Dec 2014	Jan-Jun 2015
KPL Mahmoodiah	Clinic launched 2009 Club since 2013	553 (128)	1460 (417)	300 (504)	3492 (688)	NA	39	56	68	NA	39	17	11	1 launching	5	18	5
KK Sultan Ismail	Clinic launched 2013	No clinic for older people				NA	43	36	25	NA	18	14	25	NA	3	4	1
KK Tampoi	Club launched in 2000 – 937 members	No clinic for older people				285	158	96	102	8	10	3	1	5	3	7	5
Other Clinics	**Only *KK Ulu Tiram* had Elderly Wellness Clinic and Club in the late 90s and was a pilot project in the district of Johor Bahru towards the call to implement the policy. A rehabilitation and occupational therapy unit and a clinic for screening health issues and decline in cognitive function among the older people were set up. Due to floods in year 2000, most of the equipment was destroyed and not replaced. The clinic was shut down and the club ceased to exist. (History from Assistant Medical Officer in charge of older people programmes in KK Ulu Tiram in 1994) – Interviewed on 5th July2015. The other *Klinik Kesihatan* in this list never had an older people clinic or club to date.																

KK= Klinik Kesihatan (Health Clinic) Other clinics =KK Tiram Duku, KK Larkin, KK Tebrau, KK Majidi, KK Tmn Seri Orkid, KK Gelang Patah, KK Pasir Gudang, KK Kempas Baru, KK Tun Aminah

Table 3.4 Issues with older people wellness activities in the district of Johor Bahru

HEALTH CLINICS IN JOHOR BAHRU	NOTES
KPL Mahmoodiah	Issues found and reason:- 1) No training of staff since 2010 (only 20 in total) 2) Only health talks during health clubs 3) Poor follow up attendance in clinic as too many visits to make, no transport, older people do not keep to the appointment date 4) No motivation or commitment from staff 5) High turnover of trained staff 6) For the clinic screening drive done to increase number of patients screened but unable to examine all those screened
KK Sultan Ismail	Issues found and reason:- 1) No specific club days 2) Mostly activities based on festivals and community initiation 3) Older people self sponsor with some assistance from the health clinic

KK= klinik kesihatan (health clinic) Other clinics =KK Tiram Duku, KK Larkin, KK Tebrau, KK Majidi, KK Tmn Seri Orkid, KK Gelang Patah, KK Pasir Gudang, KK Kempas Baru, KK Tun Aminah; Information obtained from medical officer or family medicine specialist in-charge of health clinics in the district of Johor Bahru (Interviews conducted between 18th to 23rd July 2015)

Table 3.5 Issues with older people wellness activities in the district of Johor Bahru (continued)

HEALTH CLINICS IN JOHOR BAHRU	NOTES
KK Tampoi	Issues found and reason:- 1) Most of the members remain the same 2) Activities are many but on festivities 3) The most active club so far with 'taichi' and 'home visits' 4) Funding by the older people in the coverage area 5) Purely community initiated with health clinic support (similar to NGO)
KK Ulu Tiram	Deactivated in year 2000 due to floods
Other Clinics	Issues found and reason:- 1) Never initiated any activities specifically for the older people population 2) Currently only caters to older people for non-communicable diseases (Diabetes Mellitus and Hypertension) as per general community 3) Was not a compulsory goal set by the District Health Office 4) Inadequate staff 5) No funding mechanism 6) No training

KK= klinik kesihatan (health clinic) Other clinics =KK Tiram Duku, KK Larkin, KK Tebrau, KK Majidi, KK Tmn Seri Orkid, KK Gelang Patah, KK Pasir Gudang, KK Kempas Baru, KK Tun Aminah; Information obtained from medical officer or family medicine specialist in-charge of health clinics in the district of Johor Bahru (Interviews conducted between 18th to 23rd July 2015)

3.7 Evaluation of the policy on the older people

Policy makers often focus mostly on the formulation and implementation of policies. In many instances the equally important processes of policy monitoring and evaluation are not given due attention. As aptly stated by the renown W.K.Kellogg Foundation, effective evaluation is not an 'event' that occurs at the end of the project, but an on-going process which helps decision makers better understand the project, its impact and external or internal influences to make informed decisions or rectifications (W.K.Kellogg Foundation, 1998).

Now, that we have seen how the policy was implemented in the district of Johor Bahru, this section will evaluate the complete policy process to assess the outcomes thus far. This assessment will include all older people health activities in the primary care level in Johor Bahru. As for the secondary and tertiary care, there are currently only two geriatricians in Johor who are attached to a private medical college, the Newcastle University Medicine Malaysia and not to the public health sector. Hence, continuity of referrals in Johor Bahru in geriatric care currently has to still be under non-specialist clinicians. The heuristic nature of the policy process itself demands the policy makers to ensure the policy is evaluated. There are many methods of policy evaluation done to assess the complex and challenging nature of the implemented policy and a common mode of assessment is by using the logic models (DeGroff & Cargo, 2009).

Logic models depict assumptions about the resources needed to support program activities and produce outputs, and activities and outputs to realize the intended outcomes of a program (Cooksy, Gill, & Kelly, 2001). The causal relationship between specific activities and outcome in the primary, secondary and tertiary care levels for

older people care the ‘activities’ logic model framework is used to evaluate the implementation of National Health Policy for Older Persons (2008).

Table 3.3 below depicts the activities conducted for the older people and the respective outcomes at the primary care level in Johor Bahru. Only older people who visit the local health clinics in Johor Bahru are screened for health issues. There is no active screening of older people in the community done in Johor Bahru and there is poor awareness of the availability of the Elderly Wellness Clinics in local health clinics among the older people population. The clinical management of these older people is also segregated into their various ailments and not holistic. The Elderly Wellness Clubs that are active have poor response from the community. The rehabilitative and palliative care is not sustainable in Johor Bahru due to insufficient manpower, logistic and financial resources. From the activities summarized in Table 3.3, it is seen that the older people programmes in Johor Bahru though present at various levels has not been able to provide a holistic and integrated approach in management of older people health issues

Table 3.6 Logic Model depicting activities and outcomes at the Primary Care Level in Johor Bahru

			OUTCOMES		
ACTIVITIES (PRIMARY CARE LEVEL)	**TARGET GROUP**	**SPECIFICS**	**Short term**	**Medium term**	**Long term**
Elderly Wellness Clinics - NCD and mental illness screening and management - Specialist care referrals - Screening for ageing disease	Older people	NCD and mental illness screening and management Specialist care referrals Screening done using the BSSK form provided by the Ministry	No training provided on older people health Poor awareness on the availability of the clinic – no advocacy No database for older people – screening forms kept in storage (no data mining or analysis)	Active screening of all older people who visit the health clinic No. of older people in the wellness program not increasing Appointment for wellness clinic – based on interest from the older people person	Not sustainable due to insufficient resources and commitment Too many appointments for NCD, cognition and older people clinic leading to defaulters
Elderly Wellness Clubs	Older people and care giver	Most of the activities are restricted to health talks Activities are only done in conjunction with festival as a celebration	Poor response to club and activities Staff not motivated to indulge in older people programs	Three clubs were formed to date but no increase in membership – older people not keen	Poor advocacy and social conditions not favorable to attend the club – not sustainable

NCD = non-communicable disease, BSSK = *Borang Saringan Status Kesihatan*

Table 3.7 Logic Model depicting activities and outcomes at the Primary Care Level in Johor Bahru (continued)

			OUTCOMES		
ACTIVITIES (PRIMARY CARE LEVEL)	**TARGET GROUP**	**SPECIFICS**	**Short term**	**Medium term**	**Long term**
Rehabilitative and palliative care	Poverty stricken Destitute Nursing homes Aged care homes	Provision of occupational health services and physiotherapist to deal with fall risks, activities of daily living (ADL) and instrumental activities of daily living (IADL)	Most district health clinics were equipped with physiotherapist and occupational therapist but not specific for elder care	Unable to cope with number of older people Large number of defaulters	Not sustainable due to understaffing or patient overload Logistics issues are of concern for older people
National Blue Ocean Strategy and KAR1SMA	Destitute/ Poverty stricken Institutionalized older people Home based bedridden Old folks home Dementia day care centres	Registering older people in institutions Screening using BSSK form to detect physical, mental, or abuse To provide referral services to those in need of care	Most older people are not aware of the program but do enlist financial assistance The health personnel do not provide care since they have their own care takers	More cases being screened due to monitoring activities This part of the program is directly monitored by the Prime Ministers Department	There is screening being done but no continuity of care Most older people are still dependent and not resilient

BSSK = *Borang Saringan Status Kesihatan*

3.8 Summary

This review led to the discovery that the current policy that has been formulated is very comprehensive and holistic in nature, encompassing various aspects of health and social needs. However, the drawback is only evident in the manner of implementation as most of the proposed activities and strategies were not undertaken. It is possible that too many activities that have been planned do not have the perfectly matched resources.

Though evidence is not readily available as to the reason for partial implementation of the policy, suffice to say that ageing issues have still not reached salience in the perspective of our policy makers. Furthermore, the competing needs of other marginalized or scrutinized health concerns such as maternal and child health, adolescents and poverty ridden groups usually takes precedence in developing countries.

It is evident that the awareness on the concept of frailty is lacking among our health professionals such as primary care doctors and physicians, nurses and social workers. Primary care doctors and nurses may often feel overwhelmed with the complex presentation of the health status of the older persons and are facing the challenge on ways to understand or manage them holistically. In the face of so many needs, the physician ends up focusing on individual health issues to address.

A paper by Karim (1997) found that while Malaysia was undergoing epidemiological transition and ageing, cardiovascular diseases, diabetes mellitus, cancers and injuries emerged as important cause of morbidity and mortality among the older population. The issue of concern here is that a report by the World Health Organization found that even after two decades, top disease burden for persons aged 60 and above still remains to be cardiovascular diseases, sense organ diseases and malignant neoplasm's (World Health

Organization, 2014b). The conditions that afflict the older people are not limited to the above but encompass nutritional health, mental health, social health and other physical health problems as most illnesses are inseparable from one another.

Most of these conditions are investigated further when screened using individual screening tests such as questionnaires for cognitive assessment or a general physical examination to discern conditions like diabetes and hypertension. The problem arises when a person who is being treated for one disease and seen by the general medical officer in the primary care clinic may not specifically screen for a separate condition again unless it is symptomatically warranted. This then delays early detection of several conditions which may co-exist in the older people, which when treated early may delay the disease progression. Compartmentalizing clinical conditions will not allow a holistic concept of care for these older people. This has led to the current fragmented concept of care being provided to our senior citizens.

Sensitizing our physicians, doctors, nurses and allied health personnel at the level of the primary care on the concept of frailty and the impact it can have on goals of care for a patient, would be a way forward. In Chapter 2 (Section 2.6) the importance of measuring frailty in an individual was described. The benefits included risk stratification in certain diseases, reducing hospitalization and admission rates, addressing self-care capabilities and prognosis of treatment and care. It would be a relief for the primary care health personnel that the confusion and stress which they currently face in their setting can be attributed to a condition called ‘frailty’.

Chapter 2 highlighted that frailty is a multidimensional syndrome with several factors influencing its evolution. To delay this evolution preventive and promotive health activity started at the community level by screening for frailty at the primary care level

to ensure the older people are channelled to the appropriate and needed care. This Chapter in turn found that there are several gaps in implementation of activities and for the older people especially in the district of Johor Bahru which led to discontinuity in care and a high dropout rate in participation in their own health. This is because care for the older people is not as a whole but compartmentalized by disease leading to wastage of resources. Programmes for the older people are not only lacking but underutilized due to poor resource management. In order to avoid resource wastage, incorporating the concept and screening of frailty into the policy guidelines will enable a holistic method of continuity of care and at all levels; primary, secondary and tertiary for the older people in Malaysia.

To further strengthen this needed policy change the following Chapters will determine if there is a burden of frailty in Johor Bahru and its likely correlates. Two important outcomes with respect to ageing which are healthcare utilization patterns and the caregiver burden for their respective carer will also be determined so that a guideline or policy change can be recommended to provide better care.

CHAPTER 4 GENERAL METHODOLOGY

4.1 Introduction

Every research needs a sound methodology to ensure the planned objectives are achieved. Chapters 2 and 3 describe the importance of measuring frailty in a community and its implications in a policy change. Therefore, the purpose of this chapter is to describe the methodology used to estimate the burden of frailty among the older people in Malaysia, determine the probable correlates and understand its association to patterns of healthcare utilization and care giving burden.

To start off, Section 4.2 would describe the conceptual framework of this study to meet the objectives intended in Chapter 1. Section 4.3 will describe the study design for this research followed by a detailed description of the study location in Section 4.4. The sampling frame used, sample size calculation and the sampling procedure will be covered in Sections 4.5 and 4.6. Section 4.7 deals with the description of the study population and the predetermined inclusion and exclusion criteria. The study instruments used in this research will be described in Section 4.8. Section 4.9 will describe the two validation and main study stages. The process of data collection and data management will be covered in Sections 4.10 and 4.11. The statistical analysis used to obtain the results for the objectives will be described in Section 4.12. The final two sections (Section 4.13 and 4.14) will cover the ethical approvals and sources of funding obtained to conduct this research. Section 4.15 will summarize this chapter.

4.2 Conceptual framework of the proposed research

The crux of this research is based on frail older people whose frailty status is determined using two frailty assessment tools. The two outcomes that will be focused upon would be their patterns of healthcare utilization healthcare burden and the care giver burden. Below is the conceptual framework to meet the study objectives (Figure4.1).

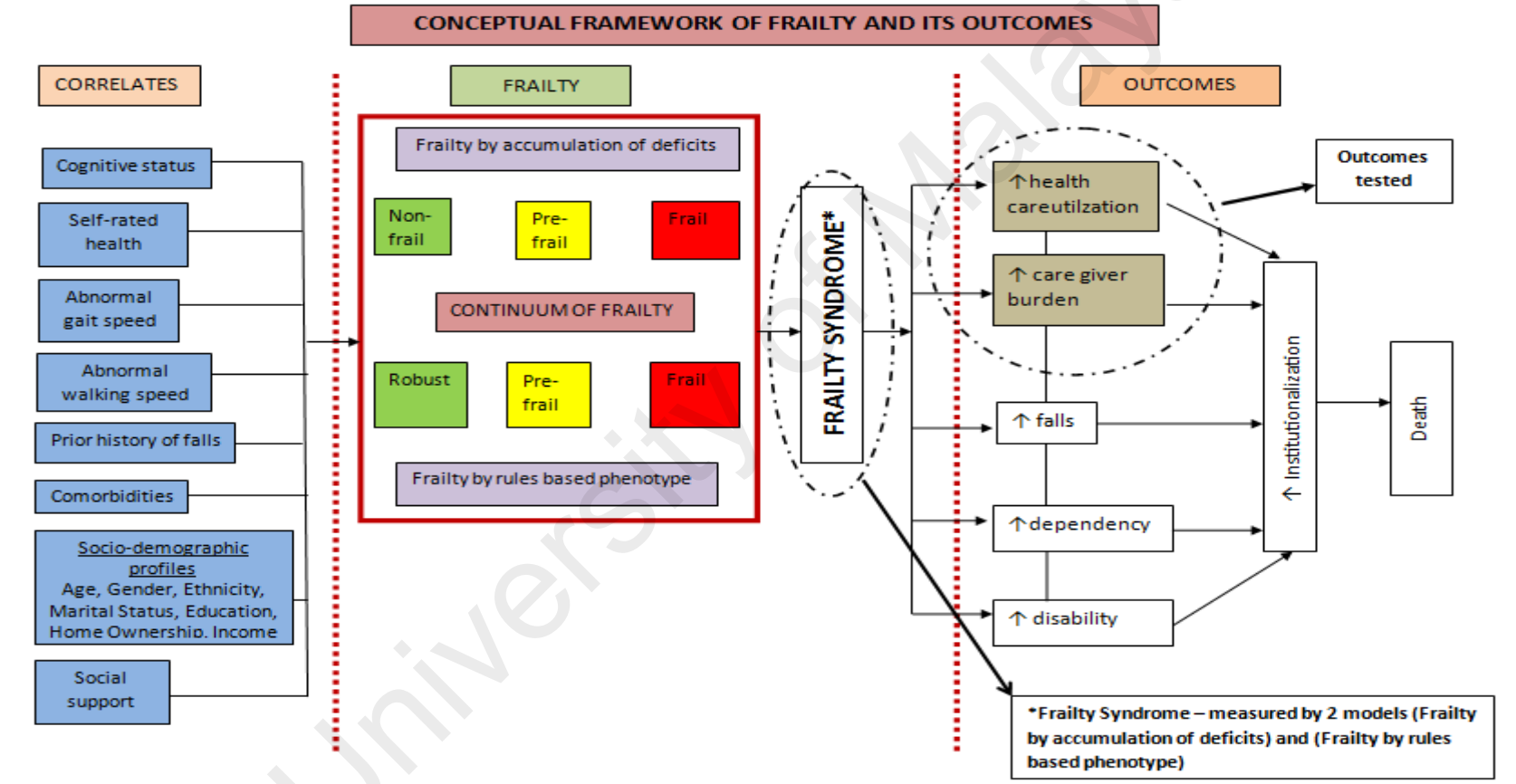

Figure 4.1 Conceptual Framework of the research depicting the continuum of frailty, its correlates and outcomes

4.3 Study design

To operationalize the conceptual framework, a cross sectional population based study was conducted involving community dwelling older people aged 60 and above residing in the district of Johor Bahru, Johor. The study was a face to face interview conducted in the household of the chosen older people. In the state of Johor, the highest number of older people aged 60 and above reside in the district of Johor Bahru (approximately 75000) (refer to Table 1.1, Chapter 1).

4.4 Study location

Based on the 2010 census, the state of Johor has a population of 3.35 million, the second most populous state in the country and a 71.9 percent level of urbanisation. Johor Bahru being the capital for the Johor State is geographically located across the Tebrau Straits from Singapore and is currently the fastest expanding district in the South Johor conurbation. The state of Johor has a high proportion of older people at approximately seven percent. The district of Johor Bahru has about 10 percent of the population aged 60 and above (Department of Statistics Malaysia, 2010). The proportion of older people in the district of Johor Bahru is as high as some states in Malaysia such as Perlis (9.2 percent) and Perak (9.4 percent).

The district of Johor Bahru is currently undergoing rapid urbanization. According to a report from the World Bank, Johor Bahru was the second largest urban area in the country just after Kuala Lumpur (World Bank Report, 2015). By 2020, the population in Johor Bahru which is projected to be 2.4 million people is expected to surpass the population in Kuala Lumpur by 2 million people (Iskandar Malaysia Macroeconomics Report, 2006). The success of urbanization does come with its fair share of challenges. Although the growth of urban areas provides opportunities for the people, there are bound to be economic and social vulnerabilities faced by these urbanites and for the

older population residing in such urban areas this situation is further compounded if they are frail. Urban expansions can also exacerbate inequality in access to services, employment, housing and health (World Bank Report, 2015).

There are private and public health facilities in Johor Bahru to cater for the health needs of these older people. However, specific geriatric care or clinics catering specially for older people are few in number which results in these older people obtaining the care that is needed from the most accessible general clinic or health practitioner. Johor Bahru is also closely situated to the economically advanced nation of Singapore, and most of the working age population tend to seek employment in Singapore. The parent-support ratio in Malaysia in 1970 was 10.8 and has been projected to rise to 14.2 by the year 2020 (Department of Statistics, 2000). Parent-support ratio refers to the number of persons aged 75 years and over per 100 persons aged 50 to 64 years old (Department of Statistics Malaysia, 2005). This measure is generally used to gauge the pressure experienced by the so called 'sandwich generation' to care for their older people while still supporting their own children which may result in unfavourable health or economic consequences for any of the three parties involved. The concern here is that the older people residing in the urban setting in Johor Bahru might be victims of this rapid urbanization and may not get the care they need or deserve.

The geographical demarcation of the district of Johor Bahru has been set by the Department of Statistics. By this division, the administrative district of Johor Bahru consists of three authority areas; *Johor Bahru Tengah, Bandar Johor Bahru and Pasir Gudang*. These administrative districts are divided based on the jurisdiction divisions of the city municipal council which is the local government authority body. Figure 4.2 is a map showing the list of areas covered by each administrative area and '*mukim*' (also

known as subdivision of district) boundary in Johor as determined by state government (Department of Statistics, Census 2010).

Figure 4.2 Map of Administrative District in Johor Bahru (inset location of Johor in Malaysia)

The following are the administrative district and '*mukims*' in Johor Bahru:

a) *Johor Bahru Tengah: Gelang Patah, Lima Kedai, Masai, Plentong, Sekudai, Ulutiram, part of Kangkar Pulai and UluChoh*
b) *Johor Bahru: Johor Bahru, Kangkar Tebrau, Pandan, remaining areas covered by Majlis Bandaraya Johor Bahru.*
c) *PasirGudang: PasirGudang*

4.5 Sample size and sampling frame

4.5.1 Sample size calculation

Sample size was calculated using a formula derived from OpenEpi Version 3-open source calculator used for prevalence studies:

$$\text{Sample size } \boldsymbol{n = [DEFF*Np\ (1\text{-}p)]/\ [(d^2/Z^2_{1\text{-}\alpha/2}*(N\text{-}1) + p*(1\text{-}p)]}$$

Where,
n = sample size

Pop. size (for finite population correction factor or fpc)(*N*):	74985
Hypothesized prevalence of frailty the population (*p*):	59.1%
Confidence limits as % of 100(absolute +/- %)(*d*):	5%
Design effect (for complex sampling - *DEFF*):	2.0

Expected prevalence for frailty; derived from a systematic review done by (Collard et al., 2012) which gave prevalence levels ranging from 4.0 - 59.1 percent. The expected prevalence is taken from this review as it takes into account both the Frailty Index and the Frailty Phenotype as instruments to measure frailty. The highest percentage of prevalence reported, 59.1 percent was used in this study.

Based on the requirements of the objective of this research, the sample required was 740 respondents (95% confidence interval). The number was further adjusted for non-response and probable migration over time at 40 percent and the final sample size required was 1048.

4.5.2 Sampling frame

The sampling of the older people aged 60 and above residing in the district of Johor Bahru was done by the Department of Statistics, Putrajaya, Malaysia. The sampling frame consisted of all older people in Johor Bahru identified from the 2010 National Census Data. (Department of Statistics, Census 2010).

To ensure representativeness of the older population in Johor Bahru, probability proportional to size (PPS) sampling procedure was used. The frame used for the selection of the sample was based on the 2010 Population and Housing Census Data. Based on this frame, Johor Bahru is divided into several enumeration blocks (EBs).

4.6 Sampling procedure

For the purpose of this research, definitions of Enumeration Blocks (EB), Living Quarters (LQ) and Household (HH) were adopted from the Department of Statistics, Malaysia. An enumeration block (EB) is a land area which is artificially created and consists of specific boundaries. Living quarters (LQ) is a place which is structurally separated and independent meant for living. A household (HH) consists of related and/or unrelated persons who usually live together and make common provisions for food and other essentials of living. The administrative district of Johor Bahru is divided into enumeration blocks (EB) consisting of approximately 80 to 120 living quarters. These living quarters (LQ) usually have approximately or 500 to 600 persons distributed across various households (HH).

EBs are geographical contiguous areas of land which identifiable boundaries created for survey operation purposes, which on average contains about 80 to 120 living quarters. Generally, all EBs are formed within gazetted boundaries i.e. within administrative districts, *mukim* or local authority areas (Department of Statistics, Census 2010). These EBs were sampled from the urban gazetted area in Johor Bahru since urbanization in

Johor Bahru is more than 94 percent. Urban areas are gazetted areas with their adjoining built up areas which have a combined population of 10,000 or more (Department of Statistics, Census 2010).

Sampling involved two stages; the Primary Sampling Unit (PSU) was the Enumeration Block (EBs) and the Secondary Sampling Unit (SSU) was the older person living within the selected EBs. The sampling of the EB (PSU) was done using PPS sampling where the larger EBs will have a bigger probability of being sampled as compared to a smaller EB. A total of 65 EBs were sampled from 3384 EBs containing older people aged 60 and above in Johor Bahru in the first stage.

In the second stage exactly the same number of older person (SSU) was sampled from each EB. This means that the older people in large EBs will have a smaller probability at being sampled and the older people in smaller EBs will have larger probability. Sixteen older people aged 60 and above were sampled from each of the selected EBs. The second stage compensates for the first stage so that each individual in the population has the same probability of being sampled. The final sample from this sampling method gave rise to 1040 older people to be recruited into the study.

All the 1040 older people sampled by the Department of Statistics who resided in Johor Bahru were visited at their home and the older people who met the inclusion and exclusion criteria (Section 4.7) were recruited into the study. There may be more than one older people residing in a living quarters, however only the older people that was sampled by the Department of Statistics was recruited into the study. The caregiver burden of the carers of these sampled older people was also assessed in this study. One caregiver per older person was identified and was required to fill a self administered questionnaire to assess the burden of caregiving.

4.7 Study population and inclusion/exclusion criteria

The study population involved all men and women aged 60 and above who were able to live in a community in the district of Johor Bahru (community dwelling). The primary caregiver identified for each older person was administered the questionnaire meant to assess the burden of caregivers (Zarit Burden Interview: ZBI). The caregiver chosen was the person whom the older person respondent identified as the person he or she depended on for his or her physical, psychological, emotional and financial needs.

4.7.1 Inclusion criteria for older people study participant

a) All men and women aged 60 and above living in the district of Johor Bahru for at least 6 months prior to the study.
b) Those who consent to participate voluntarily in the study.
c) Malaysians.

4.7.2 Exclusion criteria for older people study participant

a) Any older person living in institutions or nursing homes.
b) Those who are bedridden but living in the community (as the target population was community dwelling older people). The decision to exclude the bedridden individuals was because the frailty assessment tool included physiological measures such as height and weight, body mass index, blood pressure and pulse measurement which would not be accurate in a bed-ridden individual. Measures in the Fried's Index which include the grip strength and walking speed requires the individual to be physically able to perform as the inability to perform that indicator would be considered a deficit and cause bias. Frailty is also associated with increased incidence of bedridden days (Dupre, Gu, Warner, & Yi, 2009; Rothman, Leo-Summers, & Gill, 2008).

4.7.3 Inclusion criteria for the caregiver

a) Only the caregivers that were present in the household during the interview were recruited for the study as they were required to self administer the questionnaire.

b) Caregivers who consented to participate voluntarily in the study.

4.7.4 Exclusion criteria for the caregiver

a) Employed/Paid domestic helper. Formal caregivers such as domestic helpers or paid nurses do not experience the same burden and outcomes as informal caregiver such as family members (Timonen, 2009).

4.8 Study instruments

The main objective of this research was to determine the prevalence of frailty status and its association to the known correlates. The two outcomes that formed the further objectives were to find the association between these frail older people to their healthcare utilization patterns and the burden of care giving. Structured questionnaires were used to collect data for this research. There were two types of questionnaire; face-to-face interview and self-administered. Both types of interview had pre-tested questionnaire which were already available in a bi-lingual format (Bahasa Malaysia and English).

The face to face interview had five sections to be answered by the selected older person. The first section of the face to face interview required the full socio-demographic profile of the older person which included age, gender, marital status, ethnicity, education status, home ownership, self-rated health and the living arrangements to indicate their social support. Section 2 was to determine the cognitive status of the older respondent to decide if they required a proxy to answer the frailty and healthcare utilization questionnaire. A proxy was needed if the elderly had moderate to severe cognitive impairment during the Mini Mental State Examination (MMSE). The

cognitive status was determined using the Mini Mental State Examination (MMSE). The two frailty assessment instruments; Frailty Phenotype and Frailty index in Sections 3 and 4 were the next to be administered. Finally, the last section (Section 5) was to assess the patterns of healthcare utilization which was done using the Healthcare Utilization Questionnaire from the 2nd Malaysian National Health and Morbidity Survey.

The self administered questionnaire had two sections to be self administered by the caregiver of the selected older person. As for the caregivers, the self administered questionnaire had two sections to be completed. Section 1 contained questions on the socio-demographic profiles followed by the assessment of burden of care giving using the Zarit Burden Interview (ZBI) in Section 2. Below is the description of the study instruments used for this research:-

4.8.1 Face to face Interview

a) **Socio-demographic profiles of the older person**

The socio-demographic profiles of the older person such as the age, gender, ethnicity, marital status, education level, household income, source of social support and home ownership were assessed as part of the research to understand the demographic profile of the respondents. Apart from basic socio-demographic profiles, the older respondent was required to rate their own health status.

b) **Mini Mental State Examination (MMSE)**

The cognitive status of the older person was assessed using the Mini Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975). This tool has been widely used in research involving individuals with cognitive impairment, dementia and Alzheimer's (Fabrigoule, Lechevallier, Crasborn, Dartigues, & Orgogozo, 2003; Tangalos et al., 1996; Tierney, Szalai, Dunn, Geslani, & McDowell, 2000). This tool is

a 11- question measure that tests five areas of cognitive function: orientation, registration, attention and calculation, recall and language (Kurlowicz & Wallace, 1999). The test is scored from 0 to 30 with a cut-off for cognitive impairment of scores below 24 (Woodford & George, 2007).

The education adjusted cut-offs in Malaysia has been recommended as 14 (with no prior schooling), 17 (with at least a primary education) and 22 (those with secondary education and above) (Zarina Z.A., Zahiruddin O., & Che Wan A.H., 2007). The MMSE was chosen as it has been previously validated in the Malaysian population and is widely used in the primary care and hospital setting as a cognitive impairment screening tool (Arabi, Aziz, Abdul Aziz, Razali, & Wan Puteh, 2013). The English version of the MMSE was not found suitable to be administered due to language and cultural barriers so the Bahasa Malaysia version that has been previously validated in the Malaysian population was used.

c) **Frailty Index (based on deficit accumulation) (FI)**

The concept of frailty assessment proposed by Rockwood et al. (1994) which recognizes a complex interplay of "assets" and "deficits" that maintains or threatens the independence of these older people was used. This concept stresses on the dynamic and multidimensional nature of being frail (Rockwood & Mitnitski, 2011). Most frailty indices can be constructed using available secondary databases; however in the event of poor data availability several criteria for deficit accumulation have been suggested. The suggested criteria are the variable should be associated with health status, showing a trend which generally increases with age, it should be an attribute which saturates too early, the variables considered should cover a range of systems and the same deficits should be maintained for one iteration to the next (Searle et al., 2008). The frailty index used in this research will be described in Chapter 6 (Section 6.4.1).

d) **Frailty Phenotype (FP)**

A phenotype of frailty was proposed by L. P. Fried et al. (2001) and which had five criteria's that operationalized the concept of frailty. It was specified that frailty was identified by the presence of three or more of the characteristics from the hypothesized cycle of frailty (described in Chapter 2, Section 2.2) which are unintentional weight loss, poor grip strength, self-reported exhaustion, gait speed and low physical activity (L. P. Fried et al., 2001). The phenotypic definition of the frailty assessment tool in this study will be described in Chapter 6 (Section 6.4.1).

e) **Healthcare utilization questionnaire**

Healthcare utilization patterns were measured by a set of questions adapted from the National Health and Morbidity Survey II (NHMS II) 1996. The National Health and Morbidity Survey is the largest healthcare survey focusing on health and well-being conducted approximately every 10 years conducted by the Institute of Public Health in Malaysia (Institute of Public Health & Institute of Health Systems Research, 2012). The healthcare utilization questionnaire from the second NHMS survey was adapted as the objectives of healthcare utilization patterns in this research were similar to the framework of that questionnaire. There were four parts to the questionnaire each meant to focus on one objective regarding health status and the respective utilization. Part A had a broad screening question regarding ones' health or history of injury. Following which Part B and C consist of a series of questions which assess the patterns of those who utilize outpatient healthcare, and the reasons for not seeking care. Part D was to assess pattern of inpatient utilization. The questionnaire and the items will be described in depth in Chapter 7 (Section 7.6.1).

4.8.2 Self-administered questionnaire

a) Socio-demographic profiles of the caregiver

As for the caregiver's information on age, gender, marital status, ethnicity, income, education level and relationship with respondent were taken to understand the socio-demographic background of the caregivers of these frail older people. Operational definition of terms used in the socio-demographic profiles is given in Appendix F.

b) Zarit Burden Interview (ZBI)

Various tools have been used to measure the burden of care among the older population over the last few decades (Al-Janabi, Frew, Brouwer, Rappange, & Van Exel, 2010; Braithwaite, 1992; Brouwer, Van Exel, Van Gorp, & Redekop, 2006). The instrument Zarit Burden Interview (ZBI) used in this study was a 22 item scale proposed by (Zarit, Reever, & Bach-Peterson, 1980). It has been widely used in the assessment of burden experienced by caregivers of persons with dementia (Hébert, Bravo, & Préville, 2000). The tool will be described in detail in Chapter 8 (Section 8.8.2).

4.8.3 Other instruments

The digital weighing scale used to determine the weight measurement in kg. The height stadiometer was used for height measurement in metres. To obtain the waist-hip ratio measurement a measuring tape was used and measurement done to the nearest centimetre. The JAMAR dynamometer was used for the measurement of grip strength (North Coast Medical, Inc.) Model No. 70142. Blood pressure was obtained using a portable blood pressure monitor (Omron Model HEM-907XL). A stop watch was used to monitor duration for the 'time up and go' test.

4.9 Study Stages

The research was conducted in two stages; the first was the validation study to validate the two frailty assessment tools (Frailty index and Frailty Phenotype) and the caregiver burden tool; Zarit Burden Interview (ZBI). The methodology used for the validation study will be described in depth in Chapter 5 followed by the results. The second stage was the main research to assess the remaining objectives of the study and the results of the analytical chapters are described in Chapter 6, 7 and 8. Stage 1 was conducted from June 2012 to August 2012 and the second stage of the study was conducted from November 2012 to February 2013.

4.10 Data collection

For Stage 1 of the research which was validation of study instruments, the data collection was done by me, the principal investigator for this research. In the Stage 2 of the research, data collection was done by me and four head nurses from the health clinics in Johor Bahru. Two of the chosen head nurses for the study were of Chinese origin in case translation of general questions was needed for a respondent. The Tamil translation if needed was done by me. For each visit, the team comprised of a head nurse of Chinese origin, another head nurse and me.

The head nurses were trained on understanding the concept of frailty and the outcomes intended the measures to be obtained and how to administer the questionnaire. The training was conducted by me over three days to ensure their method of collecting data was uniform. The head nurses were only required to conduct the face to face interview with the older respondent, to obtain socio-demographic details and recording of all physiological measures such as blood pressure, height and weight measurement, calculation of body mass index, pulse measurement, waist-hip ratio. The interview and data collection process was supervised by me at all times. The head nurses also assisted

in obtaining records to confirm the answers provided by the respondent for data on age, proof of nationality, diagnosis treated for, outpatient or hospital records and bills if any.

The Mini Mental State Examination, Frailty Index, Frailty Phenotype and Healthcare utilization Questionnaires were administered by me to ensure uniformity and that no bias was introduced during classification or interpretation. The socio-demographic profiles of the caregiver and Zarit Burden Interview were self administered by the caregiver.

Prior to conducting the interview in the population, field training for administration of questionnaire was done at a health clinic to ensure the interview procedure was smoothly conducted and it was an opportunity to correct the difficulties the head nurses encountered. The whole procedure was supervised by the principal investigator.

The sample of 1040 older people provided by the Department of Statistics was distributed around the district of Johor Bahru. Each chosen older person was visited at their household and explained regarding the context and scope of the study using a Respondent Information Sheet (bilingual) (Appendix A). If they have understood, they were supplied with an informed consent form (Appendix B) and were required to sign voluntarily. An interview based questionnaire (Appendix C) was administered to the respondents which included a series of socio-demographic questions (Section One), followed by the Mini Mental State Examination (MMSE) questionnaire to test their cognitive level (Section Two). For the older respondents who scored lower than 14 (with no prior schooling), 17 (with at least a primary education) and 22 (those with secondary education and above), a proxy (primary caregiver) if needed was used to assist and complete the rest of the questionnaire which were the Frailty Index, Frailty Phenotype and the Healthcare Utilization Questionnaire. The older respondents who had cognitive impairment were also not required to answer the item for self-rated health.

Following this both the Frailty Assessment tools (multidimensional based and physical based) (Section 3) were administered. The final part of the interview consisted of answering the healthcare utilization tool (Section 4). The options of answers for Section 4 were facilitated by using a coding booklet to allow the answers to be coded into specific groups (Appendix E).

If the caregiver was present at the household, they were required to fill in their socio-demographic profiles and answer the caregiver burden tool, the Zarit Burden Interview (Appendix D) after providing informed consent. All questionnaires were available in English and Bahasa Malaysia language. All respondents were given pamphlets and health advice regarding older people health to empower them regarding their health as a token of appreciation.

Out of the 1040 older people who were visited at their residence, 794 residences had occupants at the time of the interview. 789 of them were recruited into the study as they met the inclusion and exclusion criteria. Five older persons were bedridden in their homes and under the follow up of a local health clinic. These five older people were excluded from the study. The remaining 246 residences visited did not have anyone at home or did not have the sampled older person living at the given address. Since the caregiver aspect for frail older person required a primary caregiver to be recruited, the primary caregiver for the sampled older person was recruited for the study. If the caregiver of the recruited older person was not present at the household during the interview, they were not included into the study as a second visit was not possible due to insufficient manpower and financial resources.

The final response rate for the older population was 75.3 percent (n = 789). The non respondents for the older population were adjusted for during the weighting procedure. The response rate for the caregivers was only 35.3 percent (n = 279). Therefore, the

findings presented in Chapter 8 will only represent the caregivers of the older people interviewed and cannot be generalized to the caregiver population at large.

4.11 Data management

All the data collected was checked for missing data immediately after the interview to ensure completeness to avoid missing data. If there was missing data the questions were again posed to the respondents to ensure all questions were answered. The ZBI interview which required self-administration, was also checked for completeness prior to leaving the respondents' residence. The questionnaires were appropriately coded and numbered in an ascending manner and the ZBI for each caregiver was coded to the older respondents' code to ensure uniformity and ease of data entry. All data was coded and entered by me and checked for erroneous data entry or missing data by data cleaning for each variable.

Due to the systematic approach taken during data collection and addressing any unanswered question there was no missing data in the final analysis. After data cleaning, the total scores for the data were then transformed for certain variables described below.

a) Socio-demographic variables

Among the socio-demographic variables, the age and average household income variable were re-coded into groups. The age was recorded based on the last birth date, and recoded into two groups which were young-old represented by those aged 60 to 74 and old-old represented by those aged 75 and above.

b) Average household income

The average household income was obtained as the actual income then recoded to represent four equal groups which were RM0 to RM999 for the first quartile of the

household income, RM1000 to RM2099 for the second household income quartile, RM2100 to RM3999 for the third household income quartile and equal and more than RM4000 for the last household income quartile.

c) Physical Activities

The item for physical activity was coded to ensure that options of "not involved in regular exercise" or "involved in exercise with duration less than once a week" with intensity "less vigorous than walking" as a deficit 1 and the rest scored as 0.

d) Physical Measures

The frailty index categorizes individuals to have assets and deficits; assets when the clinical measures are favourable to outcomes and deficit when they are detrimental. The body mass index, waist-hip ratio, blood pressure and sinus tachycardia were measures than were re-coded for the frailty index tool.

e) Body mass index

Body mass index was calculated as weight divided by height squared. The individuals weighing between 18.5 and 23.4 (considered normal BMI) were coded 0 (absence of a deficit) and those weighing less than 18.5 and more than 23.4 were coded as 1 (presence of a deficit). Cut-offs recommended by the Clinical Practice Guidelines on the Management of Obesity in Malaysia (Ministry of Health, Academy of Medicine Malaysia, Malaysian Association for the Study of Obesity, & Malaysian Endocrine and Metabolic Society, 2004).

f) Waist-hip ratio

The individual was required to stand with their feet apart to allow equal distribution of weight. Waist measurement was taken midway from the last rib to the tip of the iliac crest (standardized at two centimetres above the navel). Hip measurement was taken at the point of maximal protrusion of the buttock at the level of the pelvis. The measurement was taken to the nearest 0.1 centimetre. The ratio for the waist and hip

was calculated and the individuals were stratified by gender. The individuals having higher values than the predetermined cut-offs of 0.9 for men and 0.85 for women was coded as having a deficit (coded 1). Cut-offs recommended by the Clinical Practice Guidelines on the Management of Obesity in Malaysia (Ministry of Health et al., 2004).

g) Blood pressure

Blood pressure was measured using a digital blood pressure monitor. The measurement was taken in the left arm of the individual unless they had a contraindication. The average of two readings was recorded. A cut-off of equal or more than 140mmHg for the systolic blood pressure (SBP) and equal or more than 90mmHg was used to indicate a deficit and coded as 1. If the DBP was more than 90mmHg but SBP was less than 140mmHg it was also considered as a deficit. However, if the SBP was higher 140mmHg and DBP lower than 90mmHg it was not considered a deficit. The cut-off of 140/90 mmHg is as recommended in the 4th Edition of the Clinical Practice Guidelines for Management of Hypertension in Malaysia (Ministry of Health, Malaysian Society of Hypertension, & Academy of Medicine Malaysia, 2014).

h) Postural hypotension

Every individual had their blood pressure recorded in a sitting position and after one to two minutes recorded again upon standing. A drop of more than 20mmHg in the systolic blood pressure was considered as a having the condition of postural hypotension and coded as 1 to have a deficit. The cut-off for postural hypotension in older people is as recommended in the 4th Edition of the Clinical Practice Guidelines for Management of Hypertension in Malaysia (Ministry of Health et al., 2014).

The Frailty Phenotype had two physical measures that needed to be stratified at a cut-off value to indicate presence of a condition contributing to frailty. The two physical measures were the grip strength and walking speed.

i) Grip strength

Measurement of grip strength was performed with the dominant hand and elbows flexed. The participant squeezed the handle for 3-5 seconds. The measurement was repeated in the non-dominant hand. The mean of two trials of grip strength in each hand was recorded and the higher value of the two hands was used. The grip strength was stratified by body mass index (BMI) and gender. The cut off values at the 20^{th} percentile for each BMI for males and females were determined. The individuals for each group scoring lower than their cut-off were then coded as 1 to indicate (presence of a frailty criterion) and 0 to indicate its absence. Cut-offs as recommended by L. P. Fried et al. (2001). If the respondent was unable to squeeze the handle despite three attempts it was considered as presence of the frailty criteria.

j) Walking speed

The individual is required to walk a distance of 3 metres to and fro after rising from and chair and returning to it. The time taken to perform this was measured by a stop watch. The time documented in seconds is then stratified by gender and standing height. The slowest 20 percent of the population stratified by gender and standing height is used as cut-off points to determine the presence of a criterion for frailty. The presence of the criteria was coded as 1 and its absence as 0. Cut-offs as recommended by L. P. Fried et al. (2001). If the person was unable to complete the 3 metres distance it was considered as presence of the frailty criteria.

4.12 Weighting procedure of the study sample

The final data entered was population weighted prior to analysis to ensure the estimates were representative of the population. First the basic probability weight for the selected sample was applied. Next the weights were adjusted for non-response giving rise to a final adjusted weight.

Formula for calculating weights

1) Probability of each EB being sampled (Probability 1) =

   No. of older people in one EB x No. of total EBs sampled / Cumulative sum of older people in Johor Bahru

2) Probability of each older person being sampled from each EB (Probability 2) =

   No. of older people sampled in each EB/Total no. of older people in each EB

This gives rise to an overall design weight of an older peeson being sampled in Johor Bahru. The design weight is the inverse of the probability of selection.

3) Design weight = 1/ (Probability 1 x Probability 2)
4) Final weight = Design weight x non-response adjusted weight

The process of weighting for one EB is described below (example for EB1):-

Cumulative sum of older people in Johor Bahru – 74985

Total EB sampled – 65

No. of older people sampled per EB - 16

No. of older people sampled in EB1 – 52

No. of older people responded in EB1 - 12

1) 1^{st} stage sampling – EB1

   Probability 1 = 52 x 65/74985 = 4.51%

2) 2^{nd} stage sampling – older people in EB1

   Probability 2 = 16/52 = 30.77%

3) Design weight for EB1 = 1/(4.51 x 30.77) = 72.1

4) Non-response adjusted weight = 72.1 x 16/12 = 96.13

The final weight for EB1 is 96.13

The weights table for the district of Johor Bahru is given in Appendix G. The questionnaires were kept under lock and key under the surveillance of the primary investigator after data entry. The software used to enter the data was IBM Statistical Package for Social Sciences (SPSS) Version 20.0.

4.12 Statistical analysis

The data was first assessed for its distribution. If the data was normally distributed mean and standard deviation (SD) was used to describe the variables and for non- parametric data median and interquartile range was used. A descriptive analysis of the study respondents is given in Chapter 6.

Prevalence estimates were calculated for the different frailty levels by gender and described as frequency and percentages using both frailty assessment tools. Next univariate and multivariate analysis was done to determine the correlates that had an association with the frailty status and further controlled for socio-demographic determinants and cognitive status (confounders). The reference category in this analysis was the robust individuals. To assess the relationship of the variable self-rated health, only 713 older people were eligible to be assessed as the answer provided by those who had severe cognitive impairment were excluded from the analysis.

A descriptive analysis of the patterns of healthcare utilization among the older people is given in Chapter 7 using frequency and percentages stratified by their frailty status. Chapter 8 presents the prevalence of caregiver burden for each frailty level using frequency and percentage and univariate analysis of the association between frailty and caregiver burden. Multinomial logistic regression was done to describe the association of frailty and caregiver burden and further controlled for known confounders such as

socio-demographic profiles of the caregiver (Model 2) and the addition of cognitive status of the older people respondent in Model 3.

4.13 Ethical Consideration

The study involved the Malaysian population so ethical approval from two bodies was required. The first approval was from the National Medical Research Registry (NMRR) and the Medical Research and Ethics Committee (MREC) and the second from the UMMC Ethical Review Board to satisfy both the Ministry of Health and the University of Malaya regulations respectively.

- Study has been registered in NMRR - NMRR ID : NMRR-13-283-15568
- UMMC ethical approval (Reference number – 982.7) Dated - 2nd April 2013 (Appendix G)
- NMRR ethical approval (Reference number – (2)dlm.KKM/NIHSEC/800-2/2/2 Jld2.P13-452) Dated – 25 July 2013 (Appendix G)

4.14 Source of Funding

The financial support for this study was partially given by the University of Malaya Research Grant (RG461-12HTM). The rest of the funding was borne by the principal investigator.

4.15 Summary

This chapter describes the methodology that was developed. It gives an insight on how the study was designed and the choice of location for the study. It also includes a detailed description of the study population, study instruments used, sample selection and methods of data collection. An explanation on the statistical procedures used to analyze the data is also given. This cross sectional study was conducted from November 2012 to February 2013 in the district of Johor Bahru.

From this chapter we have identified three study instruments that have not been validated a priori among the Malaysian older people. The next chapter (Chapter 5) will describe the validation process for the Frailty Index, Frailty Phenotype and the Zarit Burden Interview.

CHAPTER 5 VALIDATION OF STUDY INSTRUMENT

5.1 Introduction

The importance of validating a study instrument/tool in a specific population is much more pertinent today with the multiethnic and cross-cultural society that we live in. Healthcare practitioners and clinicians are depending on this evidence based information that is provided through research to adapt and apply to their patients or target population but if this research has been conducted in another part of the globe than the targeted population, the concern would be if such findings are applicable to this group in question. There are many abstract concepts that require measurement in healthcare research and operationalization of these concepts into variables in order to develop an instrument to help quantify the phenomena (Kimberlin & Winterstein, 2008).

The process of validation is generally divided into confirming the reliability and validity of a questionnaire or study instrument.

The frailty assessment tools are categorical in nature hence inter-rater reliability, content and concurrent validity for the two frailty tools which are represented by the Frailty index and Frailty Phenotype is done. In this Chapter we discuss the two tools that have not been validated a priori among community dwelling older people aged 60 and above. The third tool, Zarit Burden Interview (ZBI) which also needs validation was tested for its test-retest reliability, internal consistency and a factor analysis to understand the dimensionality of the tool in this population.

Section 5.2 consists of a review regarding the reliability and validity of the three study instruments described above. This is followed by Sections 5.3 and 5.4 which will

describe the methods of validation used for the Frailty index and Frailty Phenotype; and Zarit Burden Interview respectively. Section 5.5 is on data management and analysis used in this chapter followed by results for the three study instruments in Sections 5.6 and 5.7. Section 5.8 consists of a discussion on the three study instruments used with their strengths and limitations and Section 5.9 gives a summary of this Chapter.

5.2 Reliability and validity of study instruments

5.2.1 Validation of Frailty Assessment Tools

It is now known that frailty is considered a global health concern but standardized approaches to measuring this dynamic state is yet to be available. Most researchers are still at the stage of developing a consensus on the definition of frailty by various International Working Groups such as The Frailty Operative Definition-Consensus Conference (FOD-CC) Project by the European Commission indicating the pathway to understanding frailty though may be painstaking is still useful in clinical settings (L. Rodríguez-Mañas et al., 2013).

There is substantial growth in the literature of frailty that show the countless ways to measure frailty and different populations that have been targeted to date. The frailty measurement tools have been validated for use by different levels of healthcare professionals. There have been tools proposed for use at a primary care level such as the Tilburg Frailty Indicator and the Groningen Frailty Indicator (Pialoux, Goyard, & Lesourd, 2012) and for geriatricians as a clinical frailty instrument such as the Edmonton Frail Scale (Rolfson, Majumdar, Tsuyuki, Tahir, & Rockwood, 2006) and the Canadian Study of Health and Aging (CSHA) Clinical Frailty Scale (Rockwood et al., 1999).

Validating a frailty tool can be specific to a type of target population; for example a specific age cut-off (R. Romero-Ortuno, 2013), among older women (Woods et al., 2005), among older men (Rochat et al., 2010), specific subsets of population such as Chinese Canadians (D. C. Chan, Tsou, Chen, & Chen, 2010), post operative groups after cardiac surgery (Opasich et al., 2010) just to name a few. Most of the frailty tools

in literature have not reported their reliability and validity results so it is rather difficult to decide which tool is best recommended for the target population of this study.

A systematic review by Bouillon et al. (2013) found that among the 27 frailty instruments described in literature today, only 26 percent of them had examined reliability and validity. Most have reported predictive validity of the tools in predicting adverse outcomes of frailty as the information is easily accessible in the database.

Frailty measurement tools have also been validated in several languages. Some tools have been translated more than others due to ease of administration. Coelho, Santos, Paul, Gobbens, and Fernandes (2014) validated the Portuguese version of the Tilburg Frailty Indicator among older community dwelling women and found their version to be valid and reliable measure of frailty among people of Portuguese culture. Frailty tool validation research has also been done in Japan. However, the frailty index known as the "Kaigo-Lobo Checklist" (CL) was different from the regular definitions of frailty used which consisted of a 15 item scale that predicted the likelihood of developing homeboundness, poor nutrition and falling (Shinkai et al., 2013).

The CL frailty index did show good concurrent validity when compared to the Fried's Frailty criteria. The KLoSHA Frailty Index (KFI) was based on the multidimensional model and correlated well with frailty indexes in the Cardiovascular Health Study when validated on 693 Korean older people (Jung et al., 2014). Researchers globally who have done work on frailty either translate an existing frailty tool and validate it in their population (Y.-J. Wang et al., 2015) or specifically include only those who speak English as their native language (Pialoux et al., 2012; Salter et al., 2015).

Since the mainstay of frailty research is to understand the ability of a tool to predict adverse outcomes, most frailty research done globally come from secondary data

analysis or longitudinal cohort studies. Mortality risk for frail relative to non-frail ranged from 1.21 to 6.03 using the phenotypic definition and 1.57 to 10.53 for those defined using the Frailty index (Bouillon et al., 2013).

Among the many frailty tools that we have today, despite vigorous attempts at validating the tools none of the frailty measurement tools can be recognized as a gold standard (Pialoux et al., 2012). This is mainly due to variations in operationalization of the concept itself which is rather intangible (Bouillon et al., 2013).

5.2.2 Validation of Zarit Burden Interview

There are various ways to measure the caregiver burden in a community and the most popular tool that appeared in almost 21 percent of studies of carer research is the Zarit Burden Interview (ZBI) (C. Jones, Edwards, & Hounsome, 2012). This tool was initially developed in 1980 to measure subjective burden among caregivers of adults with dementia (Zarit et al., 1980). The original tool consisted of 29-items that were generated based on clinical experience with caregivers and prior studies. The more widely used is the 22 item version that examines burden associated with functional/behavioural impairments and care at home. It relies on the affective response of the caregiver (Bedard et al., 2005). The American Psychological Association to date has found translation of the ZBI in several versions including Chinese, French, Japanese and Portuguese.

Over the years the tool has been modified and shortened to produce shorter versions of the burden instrument. Bedard et al. (2005) proposed a 12 item short version and four item screening version with good correlations to the original version (0.92 to 0.97 and 0.83 to 0.93) respectively. Hébert et al. (2000) brought about a 12 item short version with two dimensions as part of the Canadian Study of Health and Aging. Six short form

versions of the ZBI validated among carers of advanced cancer, dementia and acquired brain injury found that the tools had good validity, internal consistency and discriminative ability (Higginson, Gao, Jackson, Murray, & Harding, 2010). Tools with 12 items were considered most appropriate to be endorsed as a short form version and tools with one to four items can only be used for screening.

The dimensionality of the ZBI has also been investigated and produced. The Chinese version of the ZBI confirmed five factors through the Confirmatory Factor Analysis (Lu, Wang, Yang, & Feng, 2009) and the ZBI administered on Alzheimer patient caregivers identified three factors (Ankri, Andrieu, Beaufils, Grand, & Henrard, 2005). The multidimensionality implies that a clinical interpretation of the individual dimension scores could be relevant when aiming for interventions to improve burden (Ballesteros et al., 2012). Professor Luo Nan from Saw Swee Nan School of Public Health, Singapore described the various burdens one may face in care-giving using factor analysis models (Luo, 2012). He described the models involving carers of dementia patients had from two to five factors and six factor models came from carers of obsessive compulsive disorders. The ZBI has been validated in many types of caregivers; caregivers of patients with dementia (Hébert et al., 2000), the disabled older people (Arai et al., 1997), the frail older people (Stackfleth et al., 2012) and the older people with advanced illness (Higginson et al., 2010) are just some of them.

In a randomized trial involving 110 caregivers, perceived burden was at baseline more than eight points higher in caregivers sharing a household with patients compared to caregivers living separately (Melis et al., 2009). The multidimensionality of burden varies by disease process of the care-recipient, living arrangements and cultural settings.

There have been no standardized cut-off scores to determine the various levels of burden to date. Most authors adopt cut-off using quartiles (Lai, 2007) or use statistically

derived cut-off scores for predicting a condition (Schreiner, Morimoto, Arai, & Zarit, 2006). Findings from this study involved caregivers of patients with stroke; chronic obstructive pulmonary disease (COPD) and general disability suggest that a cut-off score ranging from 24–26 has significant predictive validity for identifying caregivers at risk for depression.

Formal validation of the Zarit Burden Interview in any new population has been recommended by Van Durme, Macq, and Gobert (2010) after their study results for content validity found that some of the ZBI questions were irrelevant in their study population (older people without dementia). This highlights the importance of validating the ZBI scales for specific populations prior to using the tool.

5.3 Methods for Validating Frailty Assessment Tools

The first validation process which was conducted between the months of June 2013 to August 2013 was for the two frailty assessment tools. The methodologies for sampling and data analysis are described below:-

5.3.1 Sample population and sample size

The sample of older people aged 60 and above for the validation study was recruited from eight primary care clinics in Johor Bahru. The primary care clinics that were chosen were *Klinik Kesihatan Kempas, Klinik Kesihatan Taman Universiti, Klinik Kesihatan Larkin, Klinik Kesihatan Majidee, Klinik Kesihatan Gelang Patah, Klinik Kesihatan Tampoi, Klinik Pesakit Luar Mahmoodiah and Klinik Kesihatan Pasir Gudang*. These clinics were chosen as they catered for general population which included the community dwelling older people.

Seven older persons aged 60 and above participated in the pretesting and another 50 of them participated in the pilot to ensure feasibility. The final step was to obtain a sample

of older participants who were required for the two frailty assessment tools (Frailty Index and Frailty Phenotype). In a review done by Anthoine, Moret, Regnault, Sébille, and Hardouin (2014) the median value of subject to item ratio to decide sample size for validation studies was 10 (range: one to 527). According to Osborne and Costello (2004) most guidelines for sample size required for validation studies call for a subject to item ratio of 10:1 or more. The Frailty Index had 40 items in the tool therefore 400 older persons was needed for the validation study.

5.3.2 Translation of questionnaire

Both the Frailty index and Frailty Phenotype Assessment Tools were translated into Bahasa Malaysia language by two professional translators from the Linguistics Department in the University of Malaya. The method used by these professional translators was forward and back translation and then synthesized by the head of their department to achieve semantic and conceptual equivalence. Most of the questions required only a dichotomous answer hence the normative equivalence of a questionnaire was not really a perspective to be considered here. The objectively measured values by instruments were ensured for recent and proper calibration and training for the three other interviewers was done over three cycles and reproducibility was tested during the pretesting and pilot phases.

5.3.3 Pretesting and pilot

Prior to conducting the main study the Bahasa Malaysia translated Frailty Index and Frailty Phenotype questionnaire was administered to seven older patients above the age of 60 in an outpatient clinic. All chosen older people were fluent in Bahasa Malaysia or English. There were two Malays, three Indians and two Chinese older people who participated in the pretesting. Any discrepancy in the understanding of the words was clarified and corrected.

The next step was to conduct a pilot study in one outpatient clinic in Johor Bahru involving 50 older people. The feasibility of administering the questionnaire was tested. The time taken for each interview was evaluated and ensured for ease in administration. All the participants in the pilot study understood and answered the questionnaire. The older participants were also able to perform the objective measurements required from them such as the grip strength and 'timed up and go' test. Some of the weak individuals were unable to complete the 'timed up and go' test due to exhaustion so these individuals directly scored 1 positive score for walking speed.

5.3.4 Data Collection

The total duration of the validation study was six weeks (5th June 2013 to 20th August 2013). Four hundred older patients attending eight primary care clinics in Johor Bahru were randomly selected to participate in the validation studies. The older respondents were explained regarding the study process and objectives and an informed consent (Appendix B) was obtained prior to administering the questionnaire which is shown in Appendix C (socio-demographic profile of older people, mini mental state examination (MMSE), Frailty index, Frailty Phenotype and NHMS 2 Healthcare Utilization Questionnaire). First, the socio-demographic profile of the older people was obtained. They were then administered with the Mini Mental State Examination (MMSE) to assess their cognitive status. If the scores in the MMSE were below 24, the caregivers help was enlisted to answer the rest of the Frailty Assessment questionnaire and objective measures were taken from the older person. This was followed by a series of questions regarding their existing outpatient and inpatient utilization patterns over the past year. These participants were informed that a follow up call or visit was required to complete a similar form in two weeks. The respondents were again retested after two weeks to assess the test-retest reliability of the two tools. A total of 150 older

respondents were contactable after the two weeks duration. The respondents were kept track of through their outpatient records to meet them during the follow-up hospital visits. The patients who defaulted follow up in their outpatient setting were not contactable.

5.3.5 Flow Chart

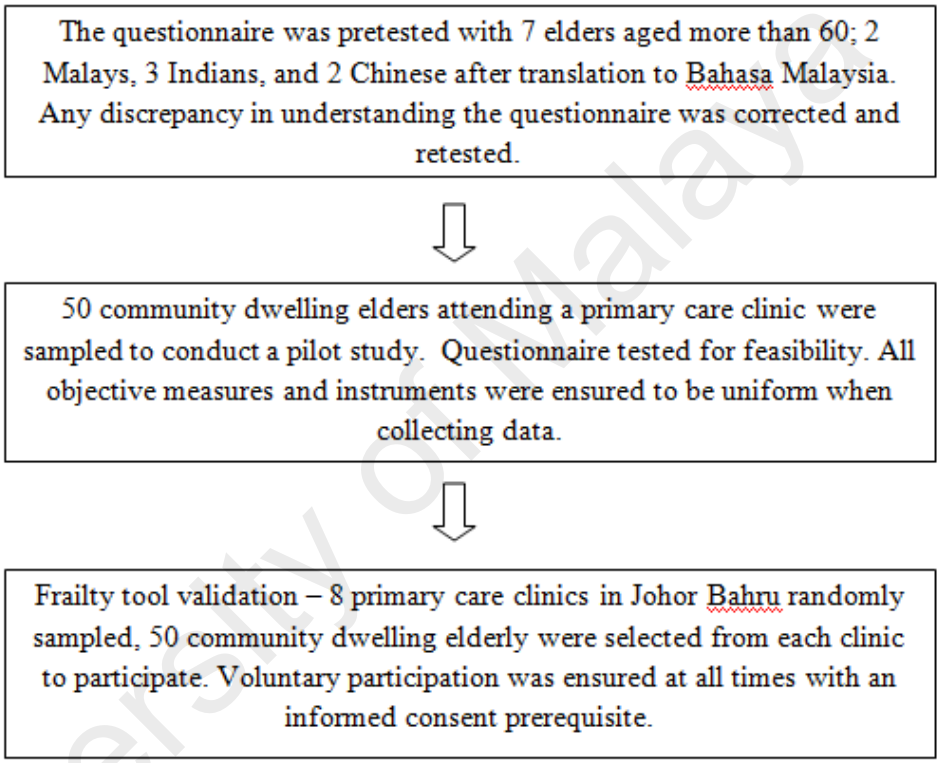

Figure 5.1 Flow Chart depicting the validation process for frailty tools

5.4 Methods for Validation of Zarit Burden Interview

The second tool to be validated was the Zarit Burden Interview which was done from August 2013 to September 2013.

5.4.1 Sample population and sample size

The sample of older people aged 60 and above with an accompanying caregiver attending three primary care clinics in Johor Bahru were recruited to participate in the

validation studies. The primary care clinics that were chosen were *Klinik Kesihatan Kempas, Klinik Pesakit Luar Mahmoodiah and Klinik Kesihatan Pasir Gudang.*

Five adult caregivers participated in the pretesting, 30 of them participated in the pilot to ensure feasibility and the final step involved 150 older people who had caregivers for the exploratory factor analysis and another 350 for the confirmatory factor analysis.

5.4.2 Translation of questionnaire

The Zarit Burden Interview (ZBI) was translated into Bahasa Malaysia language (Appendix E) with the help of two professional translators from the Linguistics Department in the University of Malaya. The methodology to translate is similar to the methods described above in Section 5.3.2.

5.4.3 Pretesting and pilot

Prior to conducting the main study the Bahasa Malaysia translated ZBI questionnaire was administered to five adults who were caregivers to the older people above the age of 60. Two of them were accompanying the older person to an outpatient clinic and the other three were community dwelling residents interviewed at home. There were two Malays, two Indians and one Chinese adult caregiver who participated in the pretesting. All the caregivers were fluent in Bahasa Malaysia. Any discrepancy in the understanding of the words was clarified and corrected.

The next step was to conduct a pilot study in one outpatient clinic in Johor Bahru involving 30 caregivers of older people. The feasibility of administering the questionnaire was tested. The time taken for each interview was evaluated and ensured for ease in administration. All the participants in the pilot study understood the questionnaire and were able to answer the questions given.

5.4.4 Data Collection

The older people who attended three primary care clinics in the district of Johor Bahru with their respective care giver were explained regarding the study objective and an informed consent was obtained from the caregiver and the care-recipient (Appendix A and E). The socio-demographic profile of the care-recipient and the caregiver was obtained first. Then the Zarit Burden Interview (ZBI) was administered to the caregiver (Appendix D). The caregiver was interviewed privately without the presence of the care-recipient to ensure privacy and accuracy in relating the experience of burden. If the caregiver chose to self administer the questionnaire, the questionnaire was then checked for completeness. The data collection was done from the 25th August 2013 to 28th September 2013.

These participants were informed that a follow up call or visit was required to complete a similar form in two weeks. A subgroup of the respondents was again retested after two weeks to assess the test-retest reliability. 60 caregivers were able to be contacted after the two week period and filled up the ZBI questionnaire. From previous literature, we know the between time assessment gap is important. An insufficient time period may allow respondents to recall their answers and too long a period may allow a change of construct. In frailty, an acute event may cause a worsening in the frailty score/level for example when assessing exhausion, pain causing reduced walking speed, falls (Frost, Reeve, Liepa, Stauffer, & Hays, 2007). It has been recommended that a 2 week period is generally appropriate to retest for health measurement scales (Streiner & Norman, 2008).

5.4.5 Flow Chart

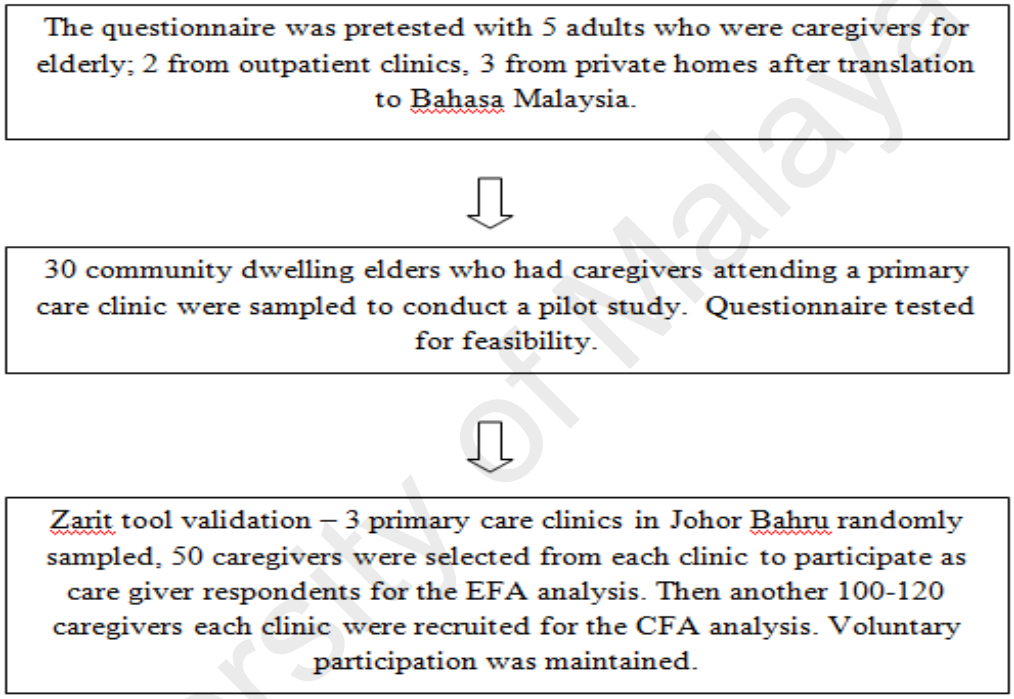

Figure 5.2 Flow chart depicting validation process of Zarit Burden Interview

5.5 Data management and analysis

All data was coded and entered into IBM Statistical Packages for Social Sciences (SPSS) Soft ware version 21.0 for analysis. Confirmatory Factor Analysis (CFA) for the Zarit Burden Interview (ZBI) was done using IBM AMOS Statistical Packages for Social Sciences (SPSS) Software version 20.0.The data was managed by me to ensure a standardized approach to cleaning, scoring and analyzing. Some of the items were stratified, transformed and recoded as described in Chapter 4 (Section 4.11).

Considering the need for early identification of individuals most vulnerable to frailty the categories of frail and pre-frail once stratified using cut-off scores were re-coded as 1 as having risk of frailty and those who were non-frail were coded as 0. This was also to allow for dichotomous dependent variables for correlation analysis. The mean and median scores for the Frailty index and Frailty Phenotype were almost similar in this population indicating a normal distribution. The Zarit Burden scores also indicated the caregiver population were distributed normally.

The two frailty assessment tools were categorical questionnaires so Kappa statistics was done for test-retest reliability. Perfect agreement would equate to a Kappa of 1 and chance agreement would equate to a 0 (Viera & Garrett, 2005). The cut-off values for the Kappa coefficients are 0.2 slight, 0.4 fair, 0.6 moderate, 0.8 substantial and 1.0 perfect agreements. Content validity of the Frailty Assessment Tools (Frailty index and Frailty Phenotype) was done by Associate Professor Dr. Shahrul Bahiyah Bt Kamaruzzaman, a geriatric consultant in the Department of Geriatric Medicine in University Malaya. She has been involved actively in work regarding frailty and sarcopenia in Malaysia and the Asian region.

Since there was no available validated or gold standard tool to measure frailty in Malaysia both tools will be used to measure frailty in this population. There is insufficient evidence currently to decide on which tool best measures the concept of frailty (Cesari et al., 2014).

The Zarit Burden Interview contained continuous variable scoring and Pearson correlation coefficient was used for test-retest reliability at two week interval. The intra-class correlation coefficient was done using a 'two-way mixed' model approach with absolute agreement. The internal consistency was tested using Cronbach alpha statistic. A Cronbach alpha of 0.8 and above has been generally considered as acceptable with a

maximum alpha value of 0.9 (Streiner, 2003). For validity studies, content validity of Zarit Burden Interview has been established by the American Psychiatric Association as a recommended tool to measure burden. The construct validity of the instrument was determined using Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA). It has been recommended by Costello and Osborne (2005) that Eigenvalues of more than 1 should be considered to determine number of factors and item communalities of magnitudes 0.4 to 0.7 can be accepted in social sciences research. Exploratory Factor Analysis (EFA) was done for the 22 item Zarit burden Interview as previous studies have shown the instrument to have different dimensions. Twenty-one items were included as the last item was a general question to encompass the burden of care-giving.

These dimensions were then used in the Confirmatory Factor Analysis (CFA) input model. The main interest in the CFA here was to know to what degree the model adequately fitted the sample data. Non-significant regression paths were removed one at a time (beginning with the least significant path) to develop a more parsimonious final model. The first index is the x^2/df ratio which standards have suggested that a small value especially if no more than three serve as an indicator of good fit (Flynn, V., & Knight, 2010). The parsimony good model fit was determined using Comparative Fit Index (CFI) and Tucker-Lewis Index (TFI) that are close to 0.95 or greater and Root Mean Square Error of Approximation (RMSEA) values are close to 0.06 (Hu & Bentler, 1999).

5.6 Results (Frailty Assessment Tools)

5.6.1 Socio-demographic profiles of the older respondents

Table 5.1 presents the socio-demographic characteristics of the participants in the year 2013. The 400 older participants had a mean age 68.0 (6.3). The percentage distributions indicate more females (53.3 percent) and majority Chinese (48 percent). More than 90 percent of the participants were married and more than 40 percent of them had a secondary school education. The proportion of participants who were prefrail/frail as compared to non-frail was almost 2:1.

The percentage of participants with history of fall was 9.5 percent. The number of hospital admissions and visits to the emergency department was 3.7 percent and 10 percent respectively.

Table 5.1 Socio-demographic profiles of the older people (2013, N= 400)

Characteristics	**n (%)**
Age, mean ±SD	68.0 ± 6.3
Gender	
Male	187 (46.8)
Female	213 (53.3)
Ethnicity	
Malay	129 (32.3)
Chinese	192 (48.0)
Indian	77 (19.3)
Others	2 (0.5)
Marital status	
Single	18 (4.5)
Married	367 (91.7)
Living separately	5 (1.3)
Widow/Widower	10 (2.5)

Table 5.1 Socio-demographic profiles of the older people (2013, N= 400) (continued)

Characteristics	n (%)
Education level	
No schooling/formal school	69 (17.2)
Primary school	132 (33.0)
Secondary school	162 (40.5)
Form6/Diploma/Certificate	25 (6.3)
Degree (Bachelors/Masters/PhD)	12 (3.0)
Frailty index	
Non-frail	146 (36.5)
Pre-frail/Frail	254 (63.5)
Fried's Phenotype	
Robust	133 (33.3)
Pre-frail/Frail	267 (66.7)
Fall History	
No fall	362 (90.5)
1 fall	33 (8.2)
2-4 falls	5 (1.3)
Hospitalization	
No admission	385 (96.3)
1 admission	11(2.7)
≥ 2 admission	4 (1.0)
Visits to ED	
No visit	360 (90.0)
1 visit	26 (6.5)
≥ 2 visits	14 (3.5)

5.6.2 Internal Reliability of Frailty index and Frailty Phenotype

Table 5.2 depicts the absolute agreement between two interviewers for all items in the Frailty index. The items were divided into domains to depict the Kappa statistics. Items assessing visual and hearing, cardiovascular and respiratory signs and symptoms and physiological measures obtained high values indicating almost perfect agreement. Lower ranges were seen for items measuring physical measures and co-morbidities but still indicating substantial agreement.

Table 5.2 Kappa statistics for items in Frailty index from test-retest reliability analysis

Variables	Item Numbers	Kappa Statistic Range
Physical measures	P1-P6	0.64-0.96
Visual and hearing measures	V1-V2, H1	0.95-0.97
Co morbidities	C11-C26	0.66- 1.0
Signs and Symptoms	S27-S32	0.90-1.0
Psychological measures	D33-D36	0.95-1.0

Kappa statistic for items in the Frailty Phenotype questionnaire is depicted in Table 5.3. The items self-reported exhaustion, unexpected weight loss and physical activity had almost perfect Kappa statistics ranging from 0.98 to 1.0. However, both objective measures did not achieve similar results but had scores of 0.82 for grip strength measures indicating substantial agreement and 0.45 for walking speed indicating moderate agreement.

Table 5.3 Kappa statistics for items in Frailty Phenotype from test-retest reliability analysis

Variables	Item Numbers	Kappa Statistic
Self reported exhaustion	F1	0.99
Unexpected weight loss	F2	0.98
Grip strength	F3	0.82
Walking speed	F4	0.45
Physical Activity	F5	1.0

5.7 Results (Zarit Burden Interview)

5.7.1Socio-demographic profiles of the caregivers

The caregiver characteristics are given in Table 5.5 where 62.3 percent of the respondents were males. More than two third of the male caregivers were aged 59 years and below, whereas the majority of the female caregivers were aged 60 and above (58.3 percent). Most of them were Malays (83.7 percent), married (76 percent) and had an education level of more than a primary level (58.8 percent). Almost 10 percent had no formal schooling. Among the male caregivers 52.8 percent were the children of the older people however among the female caregivers the majority were the spouse of the older people being cared for (58.3 percent). Both male and female caregivers were involved in long duration of care (more than 5 years), 48.6 percent and 62.1 percent respectively.

Table 5.5 Socio-demographic profiles of the caregiver by gender

Characteristics	Male, n = 218 (62.3%)	Female, n =132 (37.7%)	Total, n=350
Age Group			
59 and below	143(65.6)	55 (41.7)	198 (56.6)
60 and above	75 (34.4)	77 (58.3)	152 (43.4)
Ethnicity			
Malay	184 (84.4)	109 (82.6)	293 (83.7)
Chinese	22 (10.0)	15 (11.4)	37 (10.6)
Indian	12 (5.6)	8 (6.0)	20(5.7)
Marital status			
Single	35 (16.0)	22(16.7)	57 (16.3)
Married	167(76.6)	98 (74.2)	265 (75.7)
Divorced	7(3.2)	7(5.3)	14 (4.0)
Widow/widower	9(4.1)	5(3.8)	14 (4.0)

Education Level			
No school/formal school	21(9.6)	13(9.8)	34 (9.7)
Primary school	67 (30.7)	42(31.8)	109 (31.1)
Secondary school	102 (46.8)	62 (47.0)	164 (46.9)
Form 6/ Diploma/College	18 (8.3)	10 (7.6)	28 (8.0)
Degree (Bachelor/Masters/PhD)	9 (4.6)	5 (3.8)	14 (4.0)

Table 5.5 Socio-demographic profiles of the caregiver by gender (continued)

Characteristics	**Male, n = 218 (62.3%)**	**Female, n =132 (37.7%)**	**Total, n=350**
Relationship with respondent			
Husband/Wife	81(37.2)	77(58.3)	158 (45.1)
Child	115 (52.8)	48(36.4)	163 (46.6)
Relative	6 (2.8)	2(1.5)	8 (2.3)
Friend	16 (7.2)	5(3.8)	21 (6.0)
Duration of care			
Less than 2 years	43(19.7)	15 (11.4)	58 (16.6)
2 to 5 years	69(31.7)	35(26.5)	104 (29.7)
More than 5 years	106(48.6)	82(62.1)	188(53.7)

5.7.2 Internal reliability and consistency of Zarit Burden Interview (ZBI)

Reliability coefficient using single measure intra-class correlation co-efficient was 0.92 (CI: confidence interval 0.90, 0.95) (Table 5.6). The average difference between test and retest was about 0.70 units and the largest difference was 18 units. The internal consistency reliability of the Bahasa Malaysia version of the Zarit Burden Interview (ZBI) was good (Cronbach α = 0.89). The item-total correlations ranged from 0.34 to 0.69 and the Cronbach α coefficient was the same for any of the deleted items.

Table 5.6 Descriptive Statistics and test-retest reliability of the Zarit Burden Interview

	Mean (SD)	**Difference (test-retest)**		**ICC (95%CI)**
		Mean (SD)	(Min, Max)	
Test	15.87 (10.72)	0.70 (0.31)	(-16, 18)	0.92 (0.90, 0.95)
Retest	16.97 (11.59)			

5.7.3 Exploratory Factor Analysis (EFA) of ZBI

When examined using Principal Component Analysis with Varimax rotation, three subscales formed three new factors with Eigenvalues more than 1.0 with the three factors cumulatively explaining 53.6 percent of the variance in the 21 items. Factor loadings on the three scales ranged from 0.42 to 0.80. These cut-offs for acceptance conform to the score as recommended in (Costello & Osborne, 2005). The Kaiser-Meier-Olkin (KMO) measure of sampling adequacy was excellent at 0.88 (Beavers et al., 2013).

The three underlying domains which were then renamed as a separate domain indicating the type of burden it represented which were objective burden, relationship burden and stress burden. Objective burden included items that caregivers perceived out of worry and concern for the care-recipient. The relationship burden contained items that caused negative emotions that might affect the relationship between the care-giver and recipient. The stress domain encompassed items that arise out of stressful events or environment during the care-giving process. Similar dimensions were obtained in a study by Savundaranayagam, Montgomery, and Kosloski (2010) are described here. The latent factors obtained for the items in Zarit Burden Interview for this population is depicted in Table 5.7 below.

Table 5.7 Factor loadings for the Zarit Burden Interview (ZBI) for the caregivers using Principal Component Analysis with Varimax rotation

	Stress Burden		Relationship Burden		Objective Burden
Z4	Are you ashamed of your relatives' behaviour? (0.647)	Z1	Do you think you relative demands help more than they need?(0.681)	Z7	Are you worried about your relatives' future? (0.725)
Z6	Do you think your relative is jeopardizing your relationship with family/friends?(0.606)	Z2	Do you think you do not have self time because of time spent on relative?(0.799)	Z8	Do you think your relative is dependent on you?(0.590)
Z9	Do you feel stressed when you are around your relative?(0.623)	Z3	Are you stressed taking care of relative while having own responsibilities?(0.776)	Z20	Do you feel you should do more for your relative? (0.803)
Z10	Do you think your health has deteriorated due to involvement with relative? (0.668)	Z5	Are you angry when you are with your relative? (0.416)	Z21	Do you think you could do a better job caring for your relative? (0.758)
Z11	Do you feel you have no privacy as how you wish?(0.590)	Z12	Do you feel your social life is affected due to taking care of relative?(0.623)		
Z13	Do you feel uncomfortable with your relatives' presence?(0.769)	Z14	Do you feel your relative depends on you as the sole dependent to care?(0.638)		
Z15	Do you think that you do not have enough money with your current expenses?(0.487)				
Z16	Do you think you will no longer be able to care in the future?(0.629)				
Z17	Do you feel you have lost control over your life?(0.643)				
Z18	Do you feel like passing on the care burden to others?(0.597)				
Z19	Are you confused as to what needs to be done regarding the care of your relative(0.518)				

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization. a. Rotation converged in 6 iterations.

5.7.4 Confirmatory Factor Analysis (CFA)

Based on the three factor model derived from the Exploratory Factor Analysis (EFA), CFA was done. The proportion of variance (AVE) explained by the stress factor was 0.42 with a composite reliability (CR) of 0.85. The second factor, objective burden had AVE values of 0.50 with a CR of 0.76. The last factor was the relationship burden which had an AVE of 0.56 and CR of 0.65. Table 5.8 shows the regression weights of the 16 items.

Table 5.8 Regression weights of items in the 16-item Zarit Burden Interview (ZBI)

			Unstandardized	S.E.	P	Standardized	Ave	CR
Z18	<---	SB	1.327	.161	***	.575		
Z17	<---	SB	1.139	.122	***	.691	0.420	0.851
Z16	<---	SB	1.290	.149	***	.588		
Z13	<---	SB	1.061	.116	***	.631		
Z10	<---	SB	1.486	.135	***	.682		
Z9	<---	SB	2.003	.199	***	.778		
Z6	<---	SB	1.058	.126	***	.561		
Z4	<---	SB	1.000			.579		
Z7	<---	OB	1.000			.584		
Z20	<---	OB	1.215	.140	***	.734	0.495	0.757
Z21	<---	OB	1.304	.152	***	.778		
Z1	<---	RB	1.000			.623		
Z2	<---	RB	1.287	.106	***	.868	0.547	0.646
Z3	<---	RB	1.300	.107	***	.873		
Z14	<---	RB	.975	.115	***	.535		

Ave= average variance extracted. Standardized values were cut off at more than 0.5
CR = composite reliability

Table 5.9 shows the correlation matrix for the three factors in the Zarit Burden Interview (ZBI). Correlations exceeding 0.3 are generally required to provide enough evidence to justify enough commonality in the factors (Beavers et al., 2013). The Pearson's correlation values here range from 0.42 to 0.55. The final model output with 16 items and one global question was the best fitted model for this sample population of caregivers of older people.

Table 5.9 Correlation matrix of the 3 items in the Zarit burden Interview (ZBI)

	Objective Burden	Stress burden	Relationship Burden
Objective Burden	0.495		
Stress Burden	0.084	0.420	
Relationship Burden	0.053	0.449	0.547

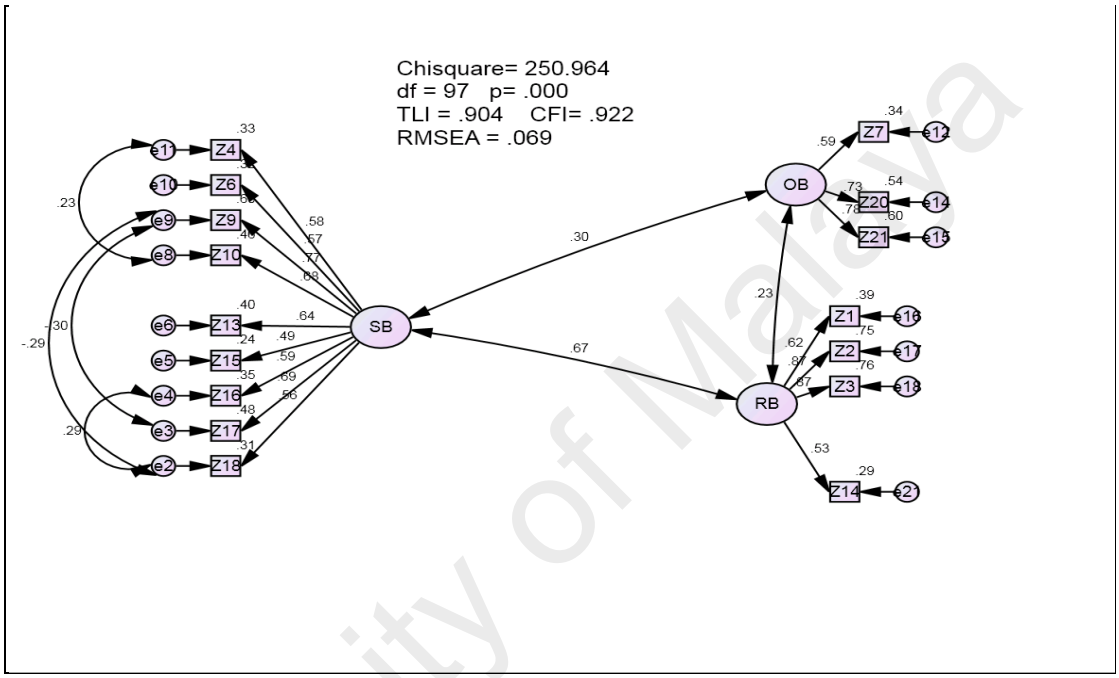

Figure 5.3 Final model output of the Zarit Burden Interview (ZBI)

The fit statistics for the final model in CFA for the Zarit Burden Interview (ZBI) is given in Table 5.10 and Figure 5.3. The X^2/df obtained in this model was 2.58 (below 3.0), Tucker-Lewis Index (TLI) and Comparative Fit Index (CFI) both more than 0.9 and Root Mean Square for Error of Approximation (RMSEA) near 0.06 which indicated a good model fit for the final model output.

Table 5.10 Fit statistics for CFA for the Zarit Burden Interview in this sample (N= 350)

	X^2	df	X^2/df	TLI	CFI	RMSEA
Fit Statistics	250.964	97	2.58	0.904	0.922	.069

5.8 Discussion

Two frailty assessment tools among community dwelling older people were used in this study. The aim was to identify a tool that had good reliability and validity to be used to predict occurrence of adverse outcomes in the future. The frailty assessment measures were based on the Frailty Index (the multidimensional concept) and the Frailty Phenotype (the physical model). There is no gold standard to date hence it was proposed that the predictive ability of a tool for adverse outcomes would likely be the most credible test (Castell et al., 2013; Metzelthin et al., 2010).

The internal reliability of the Frailty index had excellent Kappa statistics ranging from 0.9 to 1.0 for three of the domains; namely physiological measures, hearing and visual disturbances and cardiovascular or respiratory signs and symptoms. The scores for the two other domains were lower but still showing moderate to substantial agreement. The Brazilian version of the Edmonton Frail Scale (EFS) performed slightly better with Kappa coefficient of more than 0.8 (Fabrício-Wehbe et al., 2013). The discrepancy in the agreement for physical and co-morbidities domains is that likely the individuals' perception of their condition, if the condition is under control its likely not an ailment to worry about any longer. In the Frailty Phenotype all items scored high Kappa values (Kappa > 0.8) with the exception of measurement of walking speed (Kappa = 0.42). Kappa values for frailty phenotypic criteria and Study of Osteoporotic Fractures (SOF) index among men equal or more than 67 years were slightly lower at Kappa (0.59) (Ensrud et al., 2007).

Although, neither tool supersedes the other in terms of standard in fact to explain the concept, the impact of incident disability on short term measures such as healthcare utilization and burden can best be demonstrated by the physical phenotype as compared to the frailty index (Cesari et al., 2014). Thus, for the purposes of this study, even

though frailty is measured and conceptualized using both tools, the association to adverse outcomes will be measured using the Frailty Phenotype.

Frailty instruments can be divided into self-report and performance based instruments. Performance-based instruments tend to provide more precise and valid answers less influenced by the cognitive, affective, personality factors and non-response. However, it's a rather time consuming approach. Previously self reported instruments such as the Sherbrooke Postal Questionnaire, Groningen Frailty Indicator (GFI) and Tilburg Frailty Indicator (TFI) were effective choices for large population based studies to achieve high response rate (Metzelthin et al., 2010). Measures like grip strength and walking speed can now be executed with ease at a primary care level with minimal training increasing the likelihood of the Frailty Phenotype as a choice of screening tool.

The second tool that was validated in this Chapter was the Zarit Burden Interview in assessing caregiver burden experienced by carers of community dwelling older people in this population. A high intra-class coefficient value of 0.92 obtained in this study indicates the Bahasa Malaysia version has satisfactory inter-rater reliability. The Chinese version validated by Ko, Yip, Liu, and Huang (2008) in older people with dementia in Taiwan found the overall reliability to be good (ICC =0.99). The Cronbach α value reported in that Taiwan was 0.87 which similar to the internal consistency of this study. Good reliability and internal consistency values have also been reported in the Portuguese version of the ZBI (Goncalves-Pereira & Zarit, 2014). The Brazilian version of the ZBI had lower internal consistency and reliability coefficient at 0.77 and 0.88 respectively (Taub, Andreoli, & Bertolucci, 2004).

Many of the validation studies of burden using the ZBI has found that global score may not accurately predict burden in the population and that there might be some multidimensionality in the way one perceives burden. Dimensions of caregiver burden

in community dwelling older people were investigated in this study through factor analysis as the original 22 item model did not fit the data well. The result obtained a well fitted model with 17 items in three dimensional factors. The factors measured the relationship burden, objective burden and stress burden among the caregivers. The dimensional analysis in this study was similar to burdens obtained among caregivers of chronic disease (Savundaranayagam et al., 2010).

There are various models of the ZBI that has been validated around the world each with its own number of items and factors. Ballesteros et al. (2012) produced a uni-dimensional model with the reduced 12 items that measured burden all fitting well in the confirmatory factor analysis results. The 14 item three factor ZBI model validated by (Flynn L., V., & Knight, 2011) offered a parsimonious way to measure burden in clinical settings. The Alzheimer patient caregivers suggested a four factor model (Cheng, Kwok, & Lam, 2014) and the Japanese version had five factors when examined on caregivers of patients with intractable neurological disease or stroke (Miyashita et al., 2006). The factor structures help one to understand the specific structures of caregiver burden that might exist. Cultural differences and population types help determine the various dimensions that arise in the model which indicate in-depth research if it is comparable globally.

5.9 Summary

There is diversity in the available models to measure frailty that actually indicate the solitude of frailty researchers. Therefore it is essential that the tools created to define frailty though not robust at a global level should be able to measure the concept of frailty in the population concerned. This validation process of the two frailty assessment tool (FI and FP) for the urban community dwelling older population in Johor Bahru found that it had acceptable psychometric properties. However, the validity of it was suboptimum.

The limitation was time and financial constraints to refine the study tools so that they would have strong validity in this population. In future research bridging this gap is strongly recommended. Perhaps, embarking on creating a well validated frailty assessment tool for Malaysia is warranted. With that, even the measurement of burden in various subsets of population who are frail can be undertaken. There are several on-going researches across the nation exploring the concept of frailty which will assist in fine tuning the Frailty Index and Frailty Phenotype tools proposed here. The frailty tools here should not be dismissed fully as these scales are still better than chance despite weak predictive properties.

The two instruments are essentially measuring the same concept of frailty but were intended for different purposes (Martin & Brighton, 2008). The Frailty Phenotype which looks at incident disability in an individual can help predict short term outcomes such as frequency of hospitalization, numbers of outpatient visits, number of falls, need for disability benefits and need for respite care. The Frailty Index in turn helps with risk stratification with the number of deficits accumulated over time which predicts morbidity, risk of institutionalization and mortality.

In a recent review by Moorhouse and Rockwood (2012) it was shown that the Frailty Phenotype has been extensively validated to predict health outcomes such as healthcare utilization, risk of fall and dependency while the Frailty Index showed better validity to predict institutionalization and death. For public health purposes of planning future needs, the focus should be to use a tool that has ease of use with good validity and ability to identify those who are at risk of repeated outpatient visits, hospitalization and functional dependency.

From Chapters 4 and 5, we can conclude that the Frailty Phenotype is a good instrument to measure frailty in a population Frailty Phenotype of frailty assessment is a good tool to measure frailty at a community level among Malaysian older people as it requires minimal training to administer. The measurements of grip strength and walking speed are objective in nature which we know to be better than a subjective measurement tool. Direct measure also provide more precise estimates as it helps to remove the bias that is present in self-report measures (S. A. Prince et al., 2008). At the end of the day, what we aim is to have a population screening programme that is easy to administer, cost-effective, not time consuming and reliable.

For the purpose of this thesis, both tools will be used to determine the frailty status and the various correlates among the older respondents in this study (Chapter 6) as this will give an insight into the burden of frailty measured by different approaches. However, for the purpose of determining the role of frailty to healthcare utilization patterns and caregiver burden, the Frailty Phenotype classification for frailty will be used. The phenotypic definition of frailty has shown good predictive validity in measuring short term health outcomes such as healthcare utilization, physical limitation and onset of dependence (At et al., 2015; McNallan et al., 2013; O. Theou, Brothers, Mitnitski, & Rockwood, 2013; Woo, Leung, & Morley, 2012). During the validation process in this

study, the Frailty Phenotype tool showed moderately acceptable psychometric properties in this population as compared to the Frailty Index which makes it suitable to use and identify the outcomes associated with frailty.

Despite the limitations, this study adds on to the framework of frailty assessment and drawbacks one may have when validating such a tool among Malaysian older people. It is possible with representative samples of urban community dwelling older people across the states in Malaysia, this tool might have been a well validated tool to assess frailty in the population. The Frailty Assessment Tools here could be used as a screening tool at the primary care level to identify an individual at risk of frailty to be referred to a geriatric unit for a more comprehensive geriatric assessment and planned intervention.

The Zarit Burden Interview too had good psychometric properties indicating it to be a very reliable tool to measure the concept of burden. However the Bahasa Malaysia version showed three latent factors in its construct which can be identified by 17 items. The drawback of the tool was to decide upon normative cut-off values for burden levels as now the total scores range would be 0 to 68. And the quartiles for this range may not truly represent the actual burden felt and would be difficult for cross comparison across populations.

The new 17 item Zarit Burden Interview could be validated in future population subsets such as only those caring for the frail to confirm its discriminative validity in this population as compared to the original 22 item tool. The validation study population was community dwelling older people visiting a primary care and this may serve as a limitation when scoring burden with respect to the frail older people. For the purpose of this study the original scoring (score ranging from 0 to 88) will be used to measure burden and stratify them into the four groups in Chapter 8 to determine the caregiver

burden of carer's of community dwelling frail older people. This will also enable cross comparison of care-giving burden as most studies still advocate a global burden score.

CHAPTER 6 PREVALENCE OF FRAILTY AND ITS CORRELATES

6.1 Introduction

Frailty is a major health challenge associated with ageing. From the review in Chapter 2 on the background and pathophysiology of frailty, we now know that there are several factors that have been known to influence frailty. Significant work done on frail populations in the past decade has found that factors that have been associated with frailty generally belong to physical, psychological and social characteristics and co-morbidities (Nishi et al., 2012; J. Walston et al., 2006).

The aim of the present chapter is to explore the prevalence of frailty among the older people in Malaysia using two types of frailty assessment tools; Frailty Index and Frailty Phenotype and to assess the association of cognitive impairment, self-rated health, upper and lower body strength, co-morbidities and falls with frailty.

Section 6.2 provides a description of different prevalence estimates of pre-frail and frail levels and the way measurement of frailty has been operationalized globally. The next section (Section 6.3) deals with a discussion on various factors that have been known to influence the development or contribute to the worsening of frailty. Section 6.4 describes the methodology used to answer the objective of determining prevalence of frailty and its correlates in this population for the two frailty assessment tools used. Sections 6.5 and 6.6 present the results obtained using the Frailty Index and Frailty Phenotype respectively. Finally, Section 6.7 summarizes the findings obtained in this chapter.

6.2 Prevalence and determinants of frailty

Work on frailty started as early as the 1980's and due to variations in operationalized definitions of frailty, reported prevalence of pre-frailty and frailty ranges tremendously. Older people cohorts from European countries (O. Theou et al., 2013) tend to have estimates ranging from 6.1 percent to 43.9 percent, whereas the Russian cohort (Gurina, Frolova, & Degryse, 2011) had 21.1 percent to 43.9 percent frail older people and equally high numbers of pre-frail older people ranging from 24.7 percent to 64.5 percent. The prevalence estimates reported by Asian study cohorts (Auyeung, Lee, Leung, Kwok, & Woo, 2014; Imuta, Yasumura, Abe, & Fukao, 2001; Ng, Niti, Chiam, & Kua, 2006) were generally lower ranging from 5 percent to 9.2 percent. A few authors have also compiled reviews on the different prevalence estimates available among community dwelling older people globally (Collard et al., 2012). A review done by Buckinx et al. (2015) suggested that the varied definitions of frailty that exist today and the choice of screening tool could partly explain such wide ranges reported.

Many instruments for evaluating frailty have been introduced mostly suiting the needs of the researcher, clinicians or policy-makers (Sternberg et al., 2011). The studies that were done globally generally use the phenotypic measurement of frailty likely due to the ease in its reproducibility (Collard et al., 2012). The systematic review done by Collard et al. (2012) found that using different tools gave different frailty estimates in the same population. The weighted prevalence using the Frailty phenotype (physical) was 9.9 percent but 13.9 percent using the broad classification of frailty (Frailty Index) in the same population. The wide variation in prevalence is due to the various definitions and criterion that are used to operationalize this complex condition. The wide discrepancies in frailty prevalence estimates will however be of concern to policy makers who decide on resource allocation.

Table 6.1 Prevalence of frailty among community-dwelling older people

AUTHOR (YEAR)	COUNTRY	FRAILTY DEFINITION	N	PREVALENCE (%)	
				PRE-FRAIL	FRAIL
(Sternberg et al., 2011) – Systematic review from 1997-2009 (22 studies)	7 countries – Canadian Initiative on Frailty & Aging (CIFA)	Majority articles have 3 components fulfilled – physical function, gait speed and cognition.	-	-	5.0%-58.0%
(Collard et al., 2012) – Systematic review from 1998-2010 (23 studies)	United States, Canada, Italy, France, Australia, Netherlands, United Kingdom, Taiwan	Problem in ≥ 2 domains – 1 study	-		26.1%
		Fried's Frailty Index – 14 studies		44.2%	9.9%
		Frailty index – 1 study		33.5%	13.6%
		Self-report instruments – 1 study			
		a)Postal Questionnaire			55.5%
		b) Tilburg Frailty Indicator			40.2%
		c) Groningen Frailty Indicator			46.3%
(Imuta et al., 2001)	Japan	Phenotype definition			6.1%
(Holly Syddall et al., 2010)	United Kingdom	Phenotype definition	Men 320 Women318		8.5% W 4.1% M
(Gurina et al., 2011)	Russia	Fried's Model	611	65.5%	21.1%
		Steverink-Slaets Model		24.7%	32.6%
		Puts Model		42.9%	43.9%
(Garcia-Garcia et al., 2011)	Spain	Phenotype definition	2488	41.8%	8.4%
(Saum et al., 2012)	Germany	Phenotype definition	3124	49.5%	6.5%
(Garre-Olmo, Calvó-Perxas, López-Pousa, de Gracia Blanco, & Vilalta-Franch, 2013)	Spain	Physical frailty	1245		17.3%
		Social frailty			6.8%
		Mental frailty			22.8%
(O. Theou et al., 2013) - SHARE study	11 European countries	SHARE –phenotype			11.0%
		SHARE – FRAIL			6.1%
		SHARE – Groningen			43.9%
		SHARE- Tilburg			29.2%
		SHARE – CGA (Comprehensive Geriatric Assessment)			20.9%
		SHARE – FI (Frailty index)			21.6%
		SHARE – Clinical Frailty Scale			16.3%
		SHARE - Edmonton			7.6%

W=women; M=Men

Table 6.1 Prevalence of frailty among community-dwelling older people (continued)

AUTHOR (YEAR)	COUNTRY	FRAILTY DEFINITION	N	PREVALENCE (%)	
				PRE-FRAIL	FRAIL
(Moreira & Lourenco, 2013)	Brazil	Phenotype definition	847	47.3%	9.1%
(Castell et al., 2013)	Spain	Walking speed	1327		10.5%
(Jung et al., 2014)	Korea	Study of Osteoporotic Fractures (SOF)	663	49.5%	9.2%
		Fried's	621	59.4%	13.2%
		Korean Frailty Index (KFI)	668	43.0%	15.6%
(Guessous et al., 2014)	Switzerland	Phenotype definition	470	36.0%	1.3%
(Auyeung et al., 2014)	Hong Kong	Phenotype definition	4000	43.7%	5.7%
(Abizanda et al., 2014)	Singapore	Phenotype definition	1685	42.0%	5.0%
(Gale, Cooper, & Aihie Sayer, 2014)	United Kingdom	Phenotype definition	5450		14.0%
(Llibre Jde et al., 2014)	Cuba	Phenotype definition	2813		21.6%
(Biritwum R. et al., 2015)	6 countries	Frailty index (cut-off score FI>0.2)	32125		
	South Africa				36.9%
	Russia				34.1%
	Mexico				30.7%
	India				59.1%
	Ghana				40.8%
	China				13.1%
(Buttery, Busch, Gaertner, Scheidt-Nave, & Fuchs, 2015)	Germany	Phenotype definition	1843	38.3%	2.6%

W=women; M=Men

One of the salient findings from the studies enumerated in Table 6.1 is that even though the definition of older people by the World Health Organization is age 60 and above most older people studies are done from the age of 65 since the definition of 'old' is subject to specific political, economic and social factors (Ward, Parikh, & Workman, 2011). Within an economic and political context, retirement age where individuals become eligible for age-related benefits determines who is defined as 'old' or 'elderly'. Official retirement age varies between countries (Ward et al., 2011) with countries like

Australia setting it high at 70 and most Asian countries like China and Korea still a decade behind in setting the cut-off of older people's age at 60 years.

Some studies have also included ages as young as 50 (Biritwum R. et al., 2015; Guessous et al., 2014) and 55 (Abizanda et al., 2014). These studies involving younger ages allow comparison of frailty determinants between middle age and older adults. The study done by Garre-Olmo et al. (2013) in Spain included only those above the age of 75 as the focus was specifically towards mortality predictions among the old-old (aged 75 and above). The different age groups are studied to identify specific age-associated frailty determinants in morbidity and mortality predictions. Hence, reported prevalence data would not permit direct comparison and unless age matched cohorts are used.

Another issue that inadvertently affects the calculation of prevalence is the various tools that are available to measure frailty. There is no definite consensus as to which tool may be superior or preferable to precisely measure the frailty concept but currently it entirely depends on which school of thought the author is familiar or comfortable with to adapt to their study. A systematic review on 150 articles done by Bouillon et al. (2013) summarized that there were almost 27 types of frailty scales that measured frailty and 69.1 percent of them reported on Frailty Phenotype, 12 percent on Frailty index and 19 percent on one of the other 25 types. The types of items included in the frailty instrument too varied widely (types of domains included: physical functioning, disability, cognition, nutrition, mood, social support, diseases) in these 27 scales. Frailty estimates that were obtained from self-report instruments such as the Sherbrook Postal Questionnaire (SPQ), Tilburg Frailty Indicator (TFI) and Groningen Frailty Indicator (GFI) in the Netherlands tend to be very high ranging from 40.0 - 59.1 percent (Metzelthin et al., 2010). Most instruments use the similar foundation from Fried's as

their preliminary focus to create a frailty assessment tool. The only defence is this allows cross - comparison of data to some extent across the countries globally.

6.3 Factors associated with frailty

6.3.1 Socio-demographic characteristics

Age has been strongly associated with frailty and it has been repeatedly shown that the older the person is the likelihood of being frail increases (Blyth et al., 2008 142; Collard et al., 2012 88; S.E. Espinoza & Fried, 2007 1). Approximately seven percent of the U.S. population are frail and above the age of 65 and the prevalence increases to 30 percent by the age of 80 (Singh et al., 2008). So, being old does not necessarily mean one is frail but the chances of being frail most certainly increases with age (Buckinx et al., 2015). Though ageing causes a progressive decline in functional reserves, a persons' adaptation to stressors determines the rate of being frail (Fulop et al., 2010). The Frailty Index as the mean accumulation of deficits have shown an exponential increase with age (Rockwood, Mogilner, & Mitnitski, 2004) but also suggests a near maximum level at which further deficit accumulation is not sustainable (Rockwood & Mitnitski, 2006). Frailty indicators though highly associated with ages above 65 in many studies was also seen to be positively associated with middle-age adults in a Swiss cohort (Guessous et al., 2014). Frailty being a continuous process, heralds a risk of adverse outcomes even for these middle aged adults although they have not reached the age of 60 to 65 which is often the age which is used in older people studies. A cross sectional study done by R. J. Gobbens, M. A. van Assen, K. G. Luijkx, M. T. Wijnen-Sponselee, and J. M. Schols (2010) found that when frailty was segregated into specific domains such as physical, psychological and social frailty, age played a strong factor in physical frailty.

It is clear from the articles in a review by M. T. Puts, Lips, and Deeg (2005a) that frailty is definitely a syndrome afflicting the female gender more than the male. The psycho-social perspective being a determinant to the development of frailty is seen more among the older women probably because they have a higher chance of living alone due to the demise of their spouse or comparatively longer lifespan as opposed to men (R. J. Gobbens, M. A. van Assen, et al., 2010). Given the evidence above, men are not totally exempted from being frail. Jeremy Walston and Fried (1999) explored the potential protection from frailty due to gender differences and how gender can explain the rate of decline in an individual due to their inherent biological variances. It was postulated that a higher baseline level of muscle mass among men and the presence of growth hormone and testosterone which are advantageous to maintenance of muscle mass may favour the male species and the women were found to be more vulnerable to frailty in this study (Jeremy Walston & Fried, 1999).

Most frailty screening criteria and work has been done in European- American cohorts (S. E. Espinoza, Jung, & Hazuda, 2010), Mexican Americans cohorts (Al Snih et al., 2009) and recently among the Asian Taiwanese (C. Y. Chen, Wu, Chen, & Lue, 2010) and Chinese (Gu et al., 2009). African Americans were more likely to be frail than Caucasians (Holly Syddall et al., 2010). Genetic variability among various ethnic groups and their predisposition to certain illnesses with a possible influence from their socio-economic status was outlined in a book by (National Research Council (US) Panel on Race, 2004). These inherent differences among different ethnic groups need focus as they may contribute tremendously to ones' health irrespective of age.

S. E. Espinoza and Hazuda (2008) found that most frailty screening criteria have been standardized in predominantly European-American cohorts and applying them to ethnically diverse populations may result in inaccurate estimation of frailty prevalence.

However, The San Antonio Longitudinal Study of Aging found no difference in frailty prevalence between Mexican Americans and European Americans using ethnic specific criteria (conventional criteria standardized within each ethnic group) in determining frailty (S. E. Espinoza & Hazuda, 2008).

The role of ethnicity also becomes relevant when cultural perspectives influences autonomy of the older people or the power to make decisions by themselves (Hornung et al., 1998). The authors found that in multi-ethnic societies with cultural differences decisions on pertinent issues such as health and well-being is family-centric rather than at a personal level. While some genetic variability across races and ethnic groups have been associated to particular diseases the route of influence is more likely through socio-economic status and cultural influences (National Research Council (US) Panel on Race, 2004).

Marital status was linked to mental health status in community living older persons where higher rates of mental disorders were seen among those never married, separated or divorced (Kramer, German, Anthony, Von Korff, & Skinner, 1985; Trollor, Anderson, Sachdev, Brodaty, & Andrews, 2007). Marital status is a predictor of frailty and its complex interaction with living alone, dependency and mental health status makes this predictor an important variable ((ed) van Campen, February 2011).

In the Women's Health and Aging Studies, the odds of frailty highly associated with the lower socioeconomic groups; where education level and income were important predictors (Szanton, Seplaki, Thorpe, Allen, & Fried, 2010). These were the similar findings obtained by Woo J (2010) in their study of Hong Kong older population. A study done by Harttgen, Kowal, Strulik, Chatterji, and Vollmer (2013) comparing prevalence rates in higher income countries in Europe, to prevalence rates in six lower

income countries showed that those individuals with less education and income were more likely to be frail. The study also found that the level of frailty was higher in the higher income countries than in the lower income countries. Using the Fried's model the prevalence of frailty in developed countries is much lower than those measured in the developing countries (Collard et al., 2012).

Self-rated health was found to be an important predictor of frailty where measuring self-rated health facilitates exploration of health outcomes in older population (Lucicesare, Hubbard, Searle, & Rockwood, 2010). Though not ideally a socio-economic determinant of health the influence of the self rated health perspective does have an association to ones' living standard. For instance it has been seen that optimum economic conditions of an individual are prerequisites to enjoy a good state of health but more importantly education status seems to play the most important determinant in ones subjective well being (Alvarez-Galvez et al., 2013). In Japan, good self rated health was significantly associated with younger ages and employment and those with lower education status reporting poorer health (Furuya, Kondo, Yamagata, & Hashimoto, 2013). Arnadottir, Gunnarsdottir, Stenlund, and Lundin-Olsson (2011) identified a collection of body functions, activities and personal factors which are determinants of self-rated health and suggested that interventions should be targeted by public health professionals specific to these variables to influence the perception of health in old age. Frailty and self rated health have shown significant relationship where the ability to take care of one-self had the best explanatory power for community-living frail older peoples' experiences of good health (Ebrahimi et al., 2015). Among older people of Portuguese descent in Brazil, especially for women aged 80 and above, self-assessments showing worse health were from the frail category, (Melo, Falsarella, & Neri, 2014).

6.3.2 Physical domain

Bortz (2002) in his review on frailty describes that though a whole cascade of catabolic events occur due to down-regulation of hormonal, nutritional, circulatory, psychological and circadian rhythms, the entry pathway seems to still point towards the musculoskeletal system. To understand the pathology of progressive loss of muscle mass or strength one needs to appreciate the term 'sarcopenia'. Being the central focus of Fried's frailty cycle as described earlier (see Chapter 2, Figure 2.1), sarcopenia is a generic term to describe loss of muscle mass, strength and quality (Dutta, 1997). Reduced muscle mass has also been associated with imbalance and reduced speed (Bales & Ritchie, 2002; Evans, 1995) and increased falls and disability (Cooper et al., 2012; Hairi et al., 2010; Mary E. Tinetti et al., 1988). In the Women's Health and Ageing Study II (WHAS II), Frisoli Jr, Chaves, Ingham, and Fried (2011) found that sarcopenia was present in 52.9 percent frail older people and 42 percent in the pre-frail group. The deleterious effects of sarcopenia are linked to disturbances in the protein metabolism, alterations in endocrine system and stress and inflammatory processes (Michel, Lang, & Zekry, 2008).

Almost half the literature on frailty associates frailty with low physical activity and muscle weakness (Moreland, Richardson, Goldsmith, & Clase, 2004; Pelclová, Gába, Tlučáková, & Pośpiech, 2012; Olga Theou, Jakobi, Vandervoort, & Jones, 2012; J. Walston et al., 2006). Another perspective that has been studied in the physical domain is the bone mass of older men and women (Hedstrom, 1999). Sufficient supplementation of vitamin D and calcium in older men and women reduced the incidence of osteoporotic fractures and improves mobility (Rivlin, 2007).

Interventions that have been studied towards prevention of frailty in older people involves exercise routines (Binder et al., 2002; C. K. Liu & Fielding, 2011; Tribess, Virtuoso Junior, & Oliveira, 2012) and nutritional replacement (Bales & Ritchie, 2002; Johnson et al., 2011) which highlights the salience of the physical domain. Although the physical domain has taken precedence in explaining the pathogenesis of frailty, one cannot ignore the influence of psychological and social domain in the evolution of frailty.

Falls have been viewed as an age-related consequence which occurs almost inevitably in almost all older people. Nowak and Hubbard (2009) explore in their review the association between frailty and falls. Factors such as muscle strength of lower extremities, postural competence/lateral balance, impaired vision, divided attention with cognitive impairment and poly-medication have been repeatedly found as independent predictors of falls in most of the studies reviewed and incidentally a component of the frailty paradigm. Falls have been associated as a predictor of frailty in a large study involving women (Ensrud et al., 2007), among institutionalized or community dwelling older people across Europe with a range of intrinsic and extrinsic risk factors that predispose them to fall (Todd C. & Skelton D., 2004) and a higher prevalence among the frail (Fhon et al., 2013; Kathiresan G. et al., 2010). Fall related morbidity and mortality are considerably high especially among older people and the costs of healthcare related to such incidents are on the rise (Cesari et al., 2002). In Spain, the number of hospital visits due to falls especially among women and the incidence of hip fracture due to falls among the old have increased over the years which led to the development of screening for falls among the frail older people (General Directorate of Public Health, 2014).

6.3.3 Psychological domain

Another dimension of frailty studied is the psychological domain which consists of cognitive function, mood and depression (Dong et al., 2010; Rosenberg & Miller, 1992; Washburn, Sands, & Walton, 2003). The mental capacity, cognitive alertness and neurodegenerative decline that is associated with the ageing population plays a profound role in determining the quality of life of a frail older person. McCullagh et al. (2001) showed that the rate of cognitive decline is rapid among frail persons aged 65 and above and is significantly associated with Alzheimer's disease. These results were echoed in work done by Sampson (2012) who concede that this finding though common is complex and requires extensive research. Cognitive impairment is highly associated with frailty status as evidenced by many studies (Boyle, Buchman, Wilson, Leurgans, & Bennett, 2010; Robertson, Savva, & Kenny, 2013). Many tools have been used to measure cognitive status in the population but the most widely used tool is the Mini Mental State Examination in its original or modified forms (Cullen, O'Neill, Evans, Coen, & Lawlor, 2007).

A remarkable finding by Mezuk, Lohman, Dumenci, and Lapane (2012) was that frailty and depression were interrelated concepts even though the operational definitions were separate. They suggest that frailty and depression should be considered together when studying risk determinants for the older subpopulation. Studying mood disorders from the life course perspective is important to a psychiatrist. This method has brought evidence of increased rates of prevalence and recurrence of depression as age increases especially above the age of 65 (I.R. Katz, 2004).

Psychological parameter measurement (especially to assess cognitive status) among the frail has been incorporated by various frailty instruments such as Frailty Index (Rolfson

et al., 2006), Groningen Frailty Indicator (Schuurmans Hanneke, Steverink Nardi, Lindenberg Siegwart, Frieswijk Nynke, & Slaets, 2004), Tilburg Frailty Indicator (R. Gobbens, M. van Assen, K. Luijkx, R. Wijnen-Sponselee, & J. Schols, 2010) instruments proposed by 'Puts' and 'Winograd' (N. M. de Vries et al., 2011) and the Edmonton Frail Scale (Rolfson et al., 2006). Offering flexible services for the older people such as 'home healthcare' has shown considerable improvements in mood disorders, cognitive performance and activities of daily living (Di Gioacchino et al., 2004). Pharmacotherapy as an avenue to treat depression and dementia among the older people has also shown to delay frailty (Coupland et al., 2011; I. R. Katz, Curlik, & Lesher, 1988). However, most of these studies targeted institutionalized populations and requires the commitment of geriatric physicians.

6.3.4 Social domain

Social domain has been investigated as an important predictor of frailty (Andrew & Mitnitski, 2008; Washburn et al., 2003). Social support can best be defined to include two basic elements which are self-perceived number of people to turn to for support and satisfaction with the given support (Greenhill, Dix, Mellor, & Allen, 2009). Types of social support come from family, respite services, friends, neighbours and associations in the form of emotional and instrumental support, self-esteem, social integration and tangible assistance (Raube, 1992). The lack of social support is related to negative impacts on health especially for older people. It is not uncommon to find older people living alone or without a strong social framework post retirement in most countries.

The rationale of including social domain as a part of frailty definition is because frailty is associated to depression and mood disorders which are the same biological processes involved in the pathology of loneliness. The trajectory of frailty though may start with the physical domain in most studies will have social component as part of the pathway

(Bergman et al., 2007b). In Turkey, perceived social support predicted depression among the older population (Bozo, Toksabay, & Kurum, 2009). (J. E. Morley, Perry, & Miller, 2002) in his editorial on frailty explain that the absence of social support compounded by the decrease in social activity accelerates institutionalization. The presence or lack of social support has also bearing on the functional independence and the abilities to care for themselves (Gill, Williams, Richardson, & Tinetti, 1996; Nicholson, Meyer, Flatley, & Holman, 2012; Rockwood et al., 1994).

Yeh and Liu (2003)described in their study that loneliness is linked to physical and mental health problems and this domain should be factored in when planning interventions for the older people. The interventions that have been proposed for alleviating social distress among the older people in Australia for their ageing population is to provide responsive social support options such as social contacts, transport, organizing activities and lifestyle clubs (Greenhill et al., 2009).

6.3.5 Co-morbidities

Ward et al. (2011) highlighted the alarming increase in co-morbidity among older patients over 20 years from a US national survey data. Frailty and co morbidities both confer high risks for falls, hospitalization, morbidity and mortality (Michel et al., 2008). L. P. Fried et al. (2004) dissected the distinguishing characteristics of frailty, disability and co morbidities to understand that though they may be overlapping in their presentations they are different clinical entities. The findings in this study highlighted that the number of co-morbidities increased with ageing and was significantly associated with healthcare utilization and expenditure among community dwelling older people in the United States.

Specific diseases show an increased risk of developing frailty and disability (Boyd et al., 2005; Weiss, 2011). Woods et al. (2005) found that incidence of frailty was

predicted by a prior diagnosis of stroke, diabetes, hypertension, arthritis and chronic obstructive pulmonary disease. In a review associating frailty and cardiovascular diseases (CVD) nine studies showed among those who had an event of CVD the prevalence of frailty was 2.7 to 4.1 times more than healthy individuals (Afilalo, Karunananthan, Eisenberg, Alexander, & Bergman, 2009). Patients with baseline respiratory impairments were more likely to become frail and mortality highly correlated frailty with respiratory impairments (Vaz Fragoso, Enright, McAvay, Van Ness, & Gill, 2012).

Visual and hearing disturbances are important features of ageing. In studies of fall related injury visual and hearing impairments are found to be inherent risk factors of predisposing one to fall (Rubenstein, 2006). The Beaver Dam Eye Study concluded that severity of frailty was associated with deterioration in vision (Klein, Klein, Knudtson, & Lee, 2003). As early as 1998, work done by Strawbridge et.al conferred that sensory domains such as hearing, reading and recognition were associated as frailty predictors.

In a recent systematic review done spanning four databases, 35 eligible articles out of 182 full-text articles were chosen to identify the main socio-demographic factors associated with frailty and the following variables were identified: age, female gender, black race/colour (ethnicity), schooling, income, smoking, and alcohol use (Mello, Engstrom, & Alves, 2014). Health related variables that were identified in that review were self-rated health, co-morbidities, cardiovascular or respiratory illnesses, functional limitations in terms of falls, poor physical capacity or disability and cognition. Variables such as income, education and cognition had inverse associations to frailty in most studies.

6.4 Methods

The general methodology and materials used to obtain the estimated prevalence of frailty and the associated risk factors has been described in Chapter 4.

6.4.1 Study Instruments

a) Frailty Index

The respondents were evaluated for their frailty status from 40 items representing the assets and deficits which include the physical domain – stair climbing, physical exertion, activities of daily living, household chores (five items), co-morbidities – arthritis, myocardial infarction, angina, thyroid, ulcer, asthma, bronchitis, pneumonia, stroke, cancer, seizures, syncope, diabetes, hypertension, urinary incontinence, fractures (16 items), hearing domain – general diminution of hearing (one item), visual domain – general diminution of vision, diagnosed cataract, diagnosed glaucoma (three items), signs and symptoms – of cardiovascular or respiratory origins (six items), psychological symptoms – anxiety/depression/memory (four items)and physiological parameters – height, weight, BMI, waist-hip ratio, blood pressure, postural hypotension, sinus tachycardia (five items).

All outcomes were dichotomous (yes/no) or trichotomized (0 no, 0.5 maybe, 1yes) for their response. The response for each item was added to give a total value which was then standardized by dividing by total items tested (40 items). This would mean a person with four deficits when expressed as a ratio of the 40 deficits considered would have a final frailty score of 0.1. The final frailty score ranges from 0 to1 where the higher the score, the greater the frailty level. The average scores obtained were expressed as a score ranging from 0-1 (assuming that maximum deficit accumulation by theoretical definition to be 1). Based on the final scores, the respondents were categorized into three groups; those with an FI of ≤0.07as robust, FI =0.08 to 0.29 as

pre-frail and those with an FI of ≥ 0.23 as frail using two cut-points (cut-offs determined at 2 standard deviations (SD) from the average mean of the sample population) (Dupont, 2009; Rockwood et al., 2005).

b) Frailty Phenotype

There are several variants as to how these criteria have been operationalized in various studies (Rochat et al., 2010; R. Romero-Ortuno, 2011). The criteria for weight loss, self-reported exhaustion and grip strength was as per the frailty phenotype defined by Fried and colleagues, gait speed was determined using the 'timed up and go' test (Podsiadlo & Richardson, 1991) and physical inactivity using the Canadian Study for Health and Aging risk factor questionnaire (Davis, MacPherson, Merry, Wentzel, & Rockwood, 2001) using 3 questions.

This study considers those who score 0 as robust, the positive scores of 1 and 2 of the criteria as pre-frail and the positive scores of 3 to 5 criteria as frail.

6.4.2 Study variables

Table 6.2 describes the independent and dependent variables used for each frailty assessment tool. The operational definition for each domain in the Frailty Index and criterion in Frailty Phenotype is given below.

Table 6.2 Independent and dependent study variables

	Study variables	
	Independent variables	**Dependent variables**
Frailty Index	Cognitive impairment Self-rated health Upper body strength Lower body strength History of falls	Frailty will be measured by seven domains; i) Physical domain ii) Cardiovascular Symptoms and Signs iii) Respiratory Symptoms and Signs iv) Visual and Hearing Impairment v) Psychological Symptoms and Signs vi) Other co-morbidities vii) Physiological markers
Frailty Phenotype	Cognitive impairment Self-rated health Co-morbidities History of falls	Frailty will be measured by five criteria's; i) Weight loss ii) Exhaustion iii) Physical Activity iv) Grip Strength v) Walking speed

6.4.3 Confounders

Confounding refers to the degree of distortion a variable exerts in the association between the exposure and the outcome. Socio-demographic characteristics should be included in adjustments during statistical analysis due to its likely confounding effect in health related outcome studies (National Quality Forum, 2014). In this study, socio-demographic profiles such as age, gender, marital status, education level, home

ownership and household income have been found to be possible confounders in previous studies for frailty and its correlates and adjustments were done during the regression analysis (Curcio, Henao, & Gomez, 2014; Dierdre A.R., George M.S., Robert F.C., & Rose-Anne K., 2014; Sanchez-Garcia et al., 2014; Szanton et al., 2010).

6.4.4 Operational definition of variables in Frailty Index and Frailty Phenotype

a) Variables in Frailty Index

Domain	**Operational definition**
Physical domain	This domain was assessed by five questions of physical abilities
Cardiovascular symptoms and signs	This domain was assessed with three questions pertaining symptoms, signs and diagnosis of cardiovascular problems.
Respiratory Symptoms and signs	This domain was assessed using four questions pertaining respiratory symptoms, signs and diagnosis.
Visual Impairment	This domain was assessed by three questions that assess eyesight, cataract and glaucoma.
Psychological Symptoms and signs	This domain was assessed by three questions assessing depression, anxiety and memory or a diagnosis of any of the former conditions.
Other co-morbidities	This was assessed from prior knowledge of diagnosis by qualified and registered health personnel. Information was further checked from the outpatient card or books that are kept with the patient.
Physiological markers	This domain measured BMI, waist-hip ratio and postural hypotension (all values dichotomized) cut-offs by Clinical Practice Guidelines used in Malaysia.

b) Variables in Frailty Phenotype

Criterion	Operational definition
Self reported exhaustion	Self reported exhaustion assessed by a single question "In the last week, did you feel that everything you did was an effort or you could not get going?"
Unexpected weight loss	Self perceived weight loss (equal or more than five kilograms) or calculated weight loss based on formula (weight in previous year – current measured weight)/weight in previous year (at least 5 percent loss) if weight data known
Grip strength	Assessed by handgrip strength (Kg) using Jamar dynamometer. Two consecutive measurements were taken from the left and right hands. The mean value of the side recording higher grip strength will be used. The values were stratified by gender and BMI quartiles (Table 6.3).
Gait speed	This was assessed by 'timed up and go' method which was described by (Podsiadlo & Richardson, 1991). It is the time taken for a person to get up from a chair walk a distance of 3 meters, turn around, walk back and sit back on the chair. The cutoff values were stratified by height at the lowest 20th percentile for each gender (Table 6.4).
Physical Activity	Physical inactivity was assessed using three self-report questions on doing regular exercise (yes/no), the frequency (less than once weekly, one or two times weekly or three or more times weekly) and intensity of exercise (less vigorous than walking, walking or more vigorous than walking), taken from the Canadian Study of Health and Aging (CSHA) risk factor questionnaire. Physical inactivity was defined as not doing any exercise or exercise less than once weekly with intensity less vigorous than walking.

Table 6.3 Cut-offs for grip strength stratified by gender

BMI (kg/m^2)	Cut off for grip strength (kg) criteria for frailty
Male	
≤22.8	16
22.9 – 25.4	18
25.5-28.1	18
≥28.2	20
Female	
≤ 22.5	10
22.6 -25.9	8
26.0 -29.6	8.6
≥ 29.7	8.4

Table 6.4 Cut-offs for walking speed stratified by gender and height

Height (cm)	Cut off for time to walk 3 meters and back (secs)
Male	
≤ 161	≥ 10.0
>161	≥ 10.0
Female	
≤ 151	≥11.8
>151	≥ 10.0

6.4.5 Statistical Analysis

The profiles of the study participants are described using frequency and percentages. The frequency and percentages of those with cognitive impairment stratified by their education status is given for each frailty level. The self rated health had five categories in total (operational definition given in Appendix F). The very good and neither good nor poor categories had only one respondent each hence these categories were combined into the quite good categories during analysis. The reference category for this variable was quite good self-rated health.

Frailty prevalence is assessed by the two frailty assessment tools (Frailty Index and Frailty Phenotype) and percentages are given based on the previously described cut-off values (see Section 6.5.1). Univariate and multivariate regression models were done to identify factors associated with frailty (for both Frailty Index and Frailty Phenotype) which include the cognitive status, self-rated health, history of falls, grip strength and walking speed (for Frailty Index) and cognitive status, self-rated health, co-morbidities and history of falls (for Frailty Phenotype). The association between co-morbidities and frailty cannot be tested using the Frailty Index as the items that make up the index have 16 co-morbidities that are already measured which will lead to a false positive association.

The association between these variables are also tested when controlled for known confounders such as socio-demographic variables which include age, ethnicity, gender, marital status, education status, home ownership, average household income and source of income. Ordinal regression modelling for complex samples was used on the weighted sample as the outcome for frailty was ordinal in nature (non-frail/robust, pre-frail and frail).

Figure 6.1 describes the conceptual framework of this chapter and the variables that are tested.

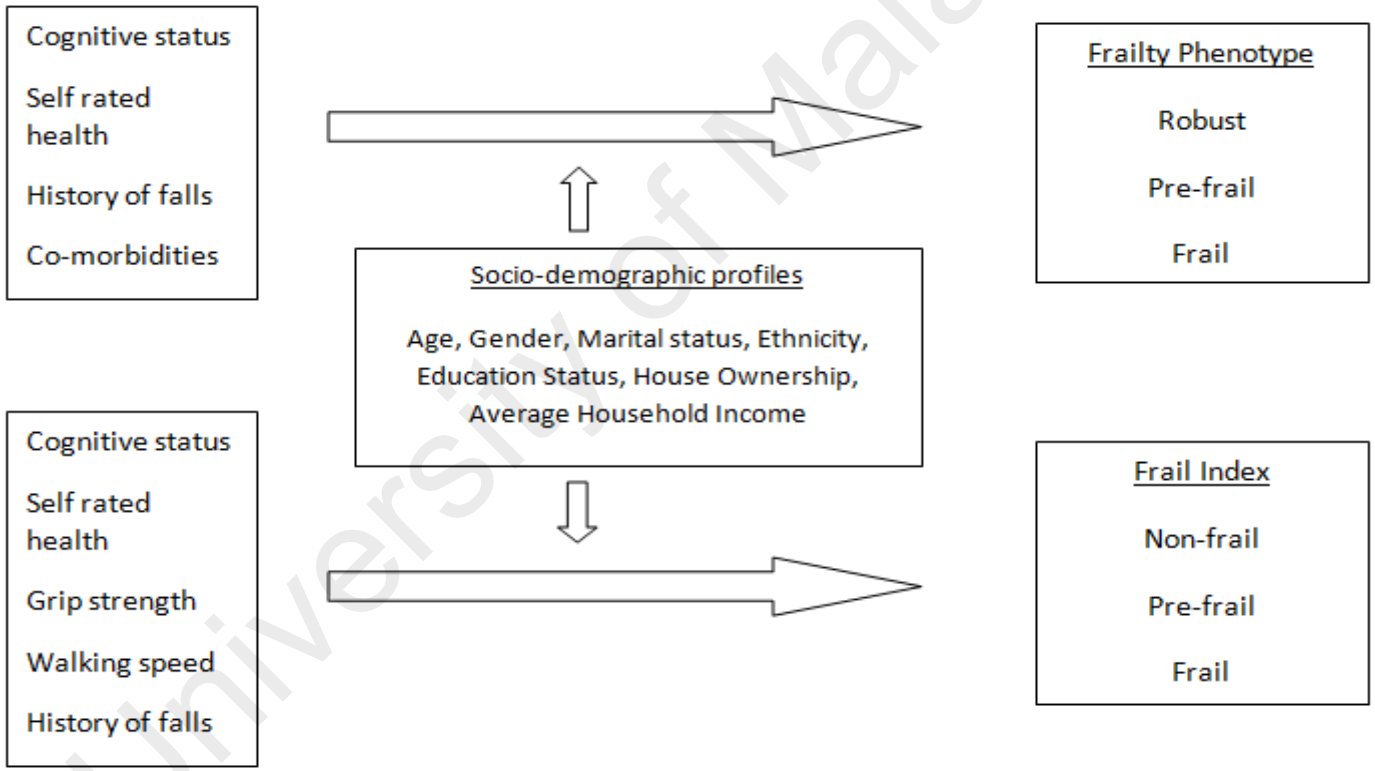

Figure 6.1 Conceptual Framework of Frailty and Associated Factors

6.5 Prevalence of frailty and its correlates measured using Frailty Index

The socio-demographic profiles of the respondents by levels of frailty (based on Frailty index) are presented in Table 6.5. The mean (standard deviation: SD) age of the studied population was 69.6 (7.2) years. Majority are Malays (83.0 percent), females (59.4 percent) and belong to the 'young old' group (74.1 percent). Most of them were married (97.0 percent). Most of the older population residing in this urban district completed at least primary school education (49.3 percent). However, almost a third of them only attended religious formal school or received no formal education.

Although the majority of them live in their own property, they are largely dependent on their children or relatives as their primary source of income (40.0 percent), whilst others depended on their own income or savings (22.0 percent). Half of the respondents report an average household income of below RM2100 and 17.5 percent of the older people live below an average household income of RM800 which is equivalent to the household poverty income line (PLI) set by the Malaysian government in the year 2010 (Zulkarnain A H & Isahaque A, 2013). Most of the respondents perceived their own health status as quite poor or very poor (85.5 percent) regardless of their frailty status.

The mean frailty score in this population was 0.13 (0.08), with scores ranging from 0 to 0.44. The mean (SD) frailty score increased significantly with age across the different age groups ($p<0.05$); 0.12(0.07) for ages 60 to 69, 0.14(0.08) for ages 70 to 79, 0.17 (0.09) for ages 80-89 and 0.18 (0.13) for ages 90 to 99. This study found that the weighted prevalence estimate of pre-frail was 67.7 percent and 5.7 percent for frail using the cut-offs 0.07 and 0.29 respectively. The rest of the population (26.6 percent) was considered non-frail with frailty scores of 0.07 and below (Table 6.5). Among those who fell into the frail category, 57.8 percent of them were in the young-old category and 71.1 percent of them females. The prevalence of frailty was 3.9 percent in the young-old

category (age 74 and below) of older people as compared to 2.9 percent among those who are old-old (aged 75 and above).

Table 6.5 Socio-demographic profiles and health status of study respondents by their frailty status (Frailty Index) and prevalence (N=789)

Characteristics		Non-frail	Prefrail	Frail
Prevalence	Frailty index	210(26.6)	534(67.7)	45(5.7)
	Cognitive impairment	14(1.8)	34 (4.3)	10 (1.3)
Age	Young-old (60-74)	161(76.7)	398(74.5)	26(57.8)
	Old-old (75 and above)	49(23.3)	136(25.5)	19(42.2)
Ethnicity	Malay	172(81.9)	445(83.3)	38(84.4)
	Chinese	32(15.2)	60(11.2)	1(2.2)
	Indian	6(2.9)	29(5.4)	6(13.3)
Gender	Male	99(47.1)	208(39.0)	13(28.9)
	Female	111(52.9)	326(61.0)	32(71.1)
Marital Status	Single	7(3.3)	7(1.3)	-
	Married	201(95.7)	519(97.2)	45(100.0)
	Separated	-	2(0.4)	-
	Divorced	-	1(0.2)	-
	Widow/Widower	2(1.0)	5(0.9)	-
Education Level	No schooling/formal school	44(21.0)	164(30.7)	20(44.4)
	Primary school	110(52.4)	258(48.3)	21(46.7)
	Secondary school	48(22.9)	89(16.7)	3(6.6)
	Form6/Diploma/Certificate	4(1.9)	15(2.8)	1(2.2)
	Degree (Bachelors/Masters/PhD)	4(1.9)	8(1.5)	-
Home Ownership	Rental	11(5.2)	12(2.2)	1(2.2)
	Own property	165(78.6)	446(83.5)	34(75.6)
	Living with family/relatives/friends	34(16.2)	76(14.2)	10(22.2)
Source of income	Pension/Welfare	31(14.8)	100(18.7)	10(22.2)
	Own income	52(24.8)	115(21.5)	7(15.6)
	From children/relatives	77(36.7)	216(40.4)	23(51.1)
	Pension & Own income	2(1.0)	5(0.9)	-
	Pension & From Children	10(4.8)	28(5.2)	1(2.2)
	Own income & From child	38(18.1)	70(13.1)	4(8.9)
Self-rated health (N=713)	Quite good	11(5.6)	69(13.8)	14(40.0)
	Quite poor	169(86.1)	400(80.0)	20(57.1)
	Very poor	16(8.2)	31(6.2)	1(2.9)
Social Support	Living alone	19(9.0)	25(4.7)	5(11.1)
	With spouse	33(15.7)	66(12.4)	3(6.7)
	With children	50(23.8)	166(31.1)	21(46.7)
	With relatives	5(2.4)	21(3.9)	-
	With friends	1(0.5)	2(0.4)	-
	With spouse and children	101(48.1)	252(47.2)	16(35.6)
	With children and relatives	1(0.5)	2(0.4)	-
Average household income	RM0-RM999	51(24.3)	137(25.7)	17(37.8)
	RM1000-RM2099	54(25.7)	132(24.7)	6(13.3)
	RM2100-RM3999	59(28.1)	161(30.1)	16(35.6)
	≥RM4000	46(21.9)	104(19.5)	6(13.3)

Ordinal regression analysis of cognitive status, self-rated health, frailty markers such as grip strength and walking speed and a history fall when regressed individually showed significant association to frailty levels. In the multivariate analysis, quite poor self-rated health (OR=0.37, 95% CI .23, .58) and very poor self rated health (OR=0.16, 95%CI .06, .45) showed a negative association to frailty levels, where as cognitive impairment (OR = 1.62, 95% CI .87, 3.03), grip strength (OR= 1.74, 95% CI 1.17, 2.58), walking speed (OR=6.15, 95% CI 3.34, 11.35) and history of falls (OR=4.58, 95% CI 3.03, 6.93) had positive associations in the multivariate analysis (see Table 6.6).

Table 6.6 Association of cognitive status, self-rated health, frailty markers and fall with frailty status (Frailty Index)

	[a]Multivariate Model						
	B	LB	UB	Exp(B)	LB	UB	Sig
Cognitive Status							
Cognitive impairment	.482	-.144	1.108	1.619	.866	3.028	.131
No cognitive impairment	0			1			
Self-rated Health							
Very poor	-1.802	-2.802	-.801	.165	.061	.449	<0.001
Quite poor	-1.002	-1.457	-.547	.367	.233	.579	<0.001
Quite good	0			1			
Frailty markers							
Grip Strength							
Abnormal	.551	.155	.948	1.736	1.167	2.581	0.006
Normal	0			1			
Walking speed							
Abnormal	1.817	1.205	2.430	6.154	3.336	11.354	<0.001
Normal	0			1			
History of fall							
Yes	1.522	1.108	1.936	4.583	3.026	6.934	<0.001
No	0			1			

[a]Multivariate model for cognitive status, self-rated health, fall and frailty markers
Link function =Logit
UB=upper boundary of confidence interval, LB=lower boundary of confidence interval, Sig=significance level, (p-value <0.05) ; pseudo R^2 =0.17

To explain the model further, socio-demographic profiles of the older people which were known confounders was added to the analysis and self rated health, abnormal grip strength, abnormal walking speed and history of falls continued to be significant correlates of frailty. Cognitive impairment was not a significant correlate of frailty. Very poor self rated health (OR=.17, 95% CI .07, .48) and quite poor self rated health (OR=.39, 95% CI .25, .63) showed negative associations to frailty. Abnormal grip strength (OR=1.69, 95% CI 1.13, 2.52), abnormal walking speed (OR=6.21, 95% CI 3.31, 11.66) and history of fall in the last year (OR=4.53, 95% CI 2.98, 6.89) showed positive associations (Table 6.7).

Table 6.7 Association of cognitive status, self-rated health, frailty markers and fall with frailty status (Frailty Index) controlled for socio-demographic profiles

	[a]Multivariate						
	B	LB	UB	Exp(B)	LB	UB	Sig
Cognitive Status							
Cognitive impairment	.359	-.274	.992	1.432	.760	2.697	0.266
No cognitive impairment	0			1			
Self-rated Health							
Very poor	-1.737	-2.737	-.738	.176	.065	.478	0.001
Quite poor	-.934	-1.397	-.470	.393	.393	.625	<0.001
Quite good	0			1			
Grip Strength							
Abnormal	.524	.125	.923	1.689	1.133	2.517	0.010
Normal	0			1			
Walking speed							
Abnormal	1.826	1.196	2.456	6.209	3.308	11.656	<0.001
Normal	0			1			
History of fall							
Yes	1.511	1.093	1.930	4.533	2.983	6.889	<0.001
No	0			1			

[a]Multivariate model for cognitive status, self-rated health, fall and frailty markers; Link function = Logit;
Model controlled for age, ethnicity, gender, marital status, homeownership, education level, monthly income, UB=upper boundary of confidence interval, LB=lower boundary of confidence interval, Sig=significance level, (p-value <0.05) ; pseudo R^2 square = 0.32

The findings in this study show that very poor and quite poor self rated health, grip strength (upper body strength), walking speed (lower body strength) and fall episodes in the last year are predictors of frailty in this study population when frailty is measured by the multidimensional framework (Frailty Index).

The results indicate that as the frailty level improves the odds of rating their health as very poor or quite poor was 5.8 and 2.6 times more as compared to rating it as quite good. The odds of having abnormal grip strength or walking speed are 1.7 times and 6.2 times higher than those with normal levels respectively. Those who have had a fall in the last one year are 4.5 times likely to have increasing frailty levels as compared to those with no history of fall. Self rated health, grip strength, walking speed and history of falls explained 17% of the model and when controlled for socio-demoraphic variables it explained 32% of the model which showed an improvement.

6.6 Prevalence of frailty and its correlates measured using Frailty Phenotype

Table 6.8 depicts the socio-demographic profiles of the study participants based on their frailty status when determined using the phenotypic definition of frailty. Most of the demographic distributions found here are similar to the findings shown in Table 6.5 where frailty was measured using the Frail Index. There are slight variations in numbers and percentages (mostly lower) in each frail group when measured using the Frailty Phenotype as compared to the broad multidimensional definition in Frailty index. Only three percent of the population were categorized as frail and 48.3 percent of them were pre-frail. The lower figures are likely due to the frailty component only addressing one domain which is the physical domain.

Table 6.8 Socio-demographic profiles and health status of study respondents by their frailty status (Frailty Phenotype) and prevalence (N=789)

Characteristics		Robust	Prefrail	Frail
Prevalence	Frailty Phenotype	384(48.7)	381(48.3)	24(3.0)
	Cognitive Impairment	26(3.3)	22 (2.8)	10 (1.3)
Age	Young-old (60-74)	292(76.0)	281(73.8)	12(50.0)
	Old-old (75 and above)	92(24.0)	100(26.2)	12(50.0)
Ethnicity	Malay	342(89.1)	291(76.4)	22(91.7)
	Chinese	30(7.8)	62(16.3)	1(4.2)
	Indian	12(3.1)	28(7.3)	1(4.2)
Gender	Male	142(37.0)	170(44.6)	8(33.3)
	Female	242(63.0)	211(55.4)	16(66.7)
Marital Status	Single	5(1.3)	9(2.4)	0
	Married	373(97.1)	368(96.5)	24(100.0)
	Living separately	2(0.5)	0	0
	Divorced	1(0.3)	0	0
	Widow/Widower	3(0.8)	4(1.0)	0
Education Level	No schooling/formal school	111(28.9)	106(27.8)	11(45.9)
	Primary school	193(50.3)	188(49.3)	8(33.3)
	Secondary school	70(18.3)	65(17.0)	5(20.8)
	Form6/Diploma/Certificate	7(1.8)	13(3.4)	0
	Degree (Bachelors/Masters/PhD)	3(0.8)	9(2.3)	0
Home Ownership	Rental	8(2.1)	16(4.2)	0
	Own property	330(85.9)	300(78.7)	15(62.5)
	Living with family/relatives/friends	46(12.6)	65(17.1)	9(37.5)
Source of income	Pension/Welfare	57(14.8)	79(20.7)	5(20.8)
	Own income	94(24.5)	76(19.9)	4(16.7)
	From children/relatives	148(38.5)	157(41.2)	11(45.8)
	Pension & Own income	2(0.5)	5(1.3)	0
	Pension & From Children	23(16.0)	15(3.9)	1(4.2)
	Own income & From child	60(15.6)	49(12.9)	3(12.5)
Self-rated health (N=713)	Quite good	33(9.2)	58(16.2)	3(21.4)
	Quite poor	314(87.7)	265(73.8)	10(71.4)
	Very poor	11(3.1)	36(10.0)	1(7.1)
Social Support	Living alone	20(5.2)	27(7.1)	2(8.3)
	With husband	57(14.8)	42(11.0)	3(12.5)
	With children	110(28.6)	113(29.7)	14(58.3)
	With relatives	12(3.1)	14(3.7)	0
	With friends	2(0.5)	1(0.3)	0
	With husband and children	181(47.1)	184(48.3)	4(16.7)
	With children and relatives	2(0.5)	0	1(4.2)
Average household income	RM0-RM999	82(21.4)	118(31.0)	5(20.8)
	RM1000-RM2099	109(28.4)	79(20.7)	4(16.7)
	RM2100-RM3999	115(29.9)	113(29.7)	8(33.3)
	≥RM4000	78(20.3)	71(18.6)	7(29.2)

Ordinal regression analysis of cognitive impairment, self-rated health, co-morbidities and history of fall with physical frailty shows only quite poor self-rated health (OR=0.46, 95% CI .29, .72) and history of falls (OR=1.16, 95% CI 1.39, 3.36) to be significant correlates of physical frailty (Table 6.9)..

Table 6.9 Association of cognitive status, self rated health, fall and co-morbid with frailty status (Frailty Phenotype)

	[a]Multivariate Model						
	B	LB	UB	Exp (B)	LB	UB	Sig
Cognitive Status							
Cognitive impairment	.353	-.337	1.043	1.424	.714	2.838	0.315
No cognitive impairment	0			1			
Self-rated Health							
Very poor	.326	-.307	.959	1.385	.735	2.609	0.313
Quite poor	-.785	-1.242	-.329	.456	.289	.720	0.001
Quite good	0			1			
Co-morbid							
Multiple	.020	-.339	.379	1.020	.712	1.461	0.914
Single	.136	-.220	.492	1.146	.803	1.636	0.453
None				1			
History of fall	.771	.330	1.211	1.161	1.391	3.358	0.001
Yes	0			1			
No							

[a] Multivariate model for cognitive status, self-rated health, falls and co morbidities
Link function =Logit
UB=upper boundary of confidence interval, LB=lower boundary of confidence interval, Sig=significance level, pseudo R^2 =0.14

Table 6.10 shows that the addition of socio-demographic variables maintained the significant association of quite poor self rated health (OR= .45, 95% CI .28, .73) and history of falls (OR=2.10, 95% CI 1.34, 3.30). Th pseudo R^2 square after controlling socio-demographic variables was 0.53. Those who rated their health as quite poor have 2.2 odds of being less frail as compared to those who have quite good self rated health. History of falls increases the likelihood of frailty by 2.1 times. Self rated health and histories of prior falls are important correlates to be taken into consideration among the

frail when measured using phenotypic definition of frailty. Self rated health and history of falls explained 14% of the model and when controlled for socio-demoraphic variables it explained 19% of the model which showed an improvement.

Table 6.10 Association of cognitive status, self rated health, fall and co-morbid with frailty status (Frailty Phenotype) controlled for socio-demographic variables

	[a]Multivariate Model						
	B	LB	UB	Exp (B)	LB	UB	Sig
Cognitive Status							
Cognitive impairment	.261	-.471	.994	1.298	.624	2.701	0.484
No cognitive impairment	0			1			
Self-rated Health							
Very poor	.181	-.512	.835	1.175	.599	3.304	0.639
Quite poor	-.797	-1.273	-.320	.451	.280	.726	0.001
Quite good	0			1			
Co-morbid							
Multiple	.013	-.357	.380	1.013	.702	1.462	0.946
Single	.165	-.203	.533	1.180	.817	1.705	0.378
None	0			1			
History of fall	.742	.290	1.194	2.100	1.336	3.299	<0.001
Yes	0			1			
No							

[a] Multivariate model for cognitive status, self-rated health, falls and co morbidities
Model controlled for age, gender, marital status, ethnicity, home ownership, education status and average monthly income
Link function =Logit
UB=upper boundary of confidence interval, LB=lower boundary of confidence interval, Sig=significance level, pseudo R^2 =0.19

6.7 Discussion

The prevalence of frailty in this study using the Frailty Index (accumulation of deficits) was 5.7 percent and 61.8 percent of the respondents were pre-frail. However, using the Frailty Phenotype definition (physical phenotype), the prevalence of frail and pre-frail were 3.0 percent and 48.3 percent respectively. Similarly, The Survey of Health, Ageing and Retirement in Europe (SHARE) involving 110,000 older respondents aged 50 years or older from 20 European countries found the prevalence of frailty differed when measured using different tools (O. Theou et al., 2013). The authors found that prevalence of frailty using the phenotype definition was only 11.0 percent however using the accumulation of deficit model the prevalence was as high as 21.6 percent. This study excluded bedridden older persons in the community since they were likely to be frail and by excluding we may underestimate the prevalence of frailty. However, the outcomes tested for utilization and caregiver burden will find significant associations for the frail category increasing the strength of study lending bias to the findings as evidenced by previous studies (Lutomski et al., 2014). The bedridden elderly will also need specific care and services which cannot be generalized to the rest of the community dwelling population.

A study done among the Korean older people comparing the use of Frailty Index and Frailty Phenotype showed only a difference of 2.4 percent in the prevalence of frailty between the two tools (Jung et al., 2014). 22.7 percent among the Canadian older persons (Rockwood, Song, & Mitnitski, 2011). A systematic review by Collard, Boter, Schoevers and Oude Voshaar reported that prevalence of frailty when measured using the physical phenotype ranged between 4.0 to 17.0 percent but studies that used accumulation of deficit model of frailty showed higher prevalence of frailty varying from 4.2 to 59.1 percent (Collard et al., 2012).

The results obtained in this study highlights that there are comparative levels of frailty in Malaysia to other Asian countries like Hong Kong (Auyeung et al., 2014) which reported 43.7 percent pre-frail older people and 5.7 percent frail older people. The prevalence of frailty in Singapore at 5.0 percent is also almost similar to the levels obtained in this study (Ng et al., 2006). Even though the prevalence of frail elder population in our study is much lower than the Europeans (O. Theou et al., 2013) and the Spanish (Garre-Olmo et al., 2013), there is a very high percentage of pre-frail older people. The lower prevalence obtained in this study is likely due to the younger age cohort (ages 60 to 74) represented by majority of the respondents. This should alert us to a potential increase in cost and burden of care of frail older people in the community in the future. While this is a cause for concern, the detection of frailty levels in the population will also allow for closer monitoring and frailty prevention strategies to be employed early.

This study also supports previous study findings of a higher prevalence of frailty among women as compared to men and that it increases with age. In a cross sectional study involving 66, 589 Canadian older people the mean score for accumulation of deficits increased exponentially with age (Rockwood et al., 2004). The SHARE study in Europe found that women were more frequently pre-frail and frail (42.0 percent and 5.2 percent respectively) than men (32.7 percent and 2.9 percent respectively) (Santos-Eggimann, Cuénoud, Spagnoli, & Junod, 2009)

The lower prevalence of frail older people in this population can also be attributed to the study being conducted in an urban setting. Comparative data for urban and rural settings done in the Beijing Longitudinal Study of Aging showed that Chinese urban dwellers showed better health and lower frailty indices than their rural counterparts (P. Yu et al., 2012). The data from the Canadian Study of Health and Ageing also showed higher

mortality among rural older people (age above 80) who are frail with few differences among the younger-old (Song, MacKnight, Latta, Mitnitski, & Rockwood, 2007).

It is known that frailty increases exponentially with age (Rockwood et al., 2004). The Weibull distribution of the Frailty index among the Chinese population further strengthens this association but a levelling off was seen by the time one reaches their 80s (Goggins, Woo, Sham, & Ho, 2005). The mean frailty index obtained in this study for each age group (from ages 60, 70, 80 and 90) was slightly lower than the scores obtained in the Survey of Health, Ageing and Retirement in Europe (SHARE) study but similarly increased in average scores across the four age groups (0.12,0.14, 0.17 and 0.18 respectively). We do know that there is an association between age and mean frailty index in that the mean values increase exponentially in older age groups. Since the variance explained by age was small in the study it is debatable if categorizing frailty accounting for age will make a difference in the association to its outcome (R. Romero-Ortuno, 2013).

Most older people experience some degree of cognitive impairment as they age, the only difference being the age of onset. Previous studies on frailty with cognitive impairment (Halil, Cemal Kizilarslanoglu, Emin Kuyumcu, Yesil, & Cruz Jentoft, 2015; Robertson et al., 2013) reveal a strong association between the two clinical entities which warrant strong advocacy and actions to weaken this inextricable link. 4.3 percent of the older people in the pre-frail group had impaired cognitive function as compared to 1.8 percent in the robust group. However, only 1.3 percent of the frail older people had cognitive impairment. Some studies globally have reported very high levels of cognitive decline among the frail. The levels obtained in this study are much lower than the results obtained in Jerusalem Longitudinal Cohort Study (which had 53.3 percent cognitive decline among the frail) (Jacobs, Cohen, Ein-Mor, Maaravi, & Stessman,

2011). This glaring difference was likely due to the different cut-off scores stratified by education status in our population whereas most of the studies use cut-off scores as high as 24 as suggested by Folstein et al. (1975). The high prevalence of cognitive impairment in the Jerusalem Longitudinal Cohort Study was also because the population researched was much older (age of 85) as compared to the population in this study (aged 60 and above). A study among the Mexican-Americans older people showed that the older people with low Mini Mental State Examination scores (cut-off 21) were independently associated with increased risk of frailty (Raji, Al Snih, Ostir, Markides, & Ottenbacher, 2010).

The results obtained in this study are however contrary to previous work where frailty is usually associated with cognitive impairment. Here, cognitive function did not show any association with frailty regardless of the definition used. The directionality of these two variables also requires further insight as it has been found that being frail can contribute to subsequent cognitive decline (Alencar, Dias, Figueiredo, & Dias, 2013). The findings of this study reiterate the need for further longitudinal studies to understand the exact role of cognitive impairment in frailty which is yet to be established to date.

Self-rated health has been shown to be a predictor of adverse health outcomes among the older people (Abizanda et al., 2011). Frailty was detected to be nearly three times higher in those who reported poor self rated health compared to those who reported good self rated health in a cohort of Spanish older people (Castell et al., 2013). This study did show an association between poor self-rated health and frail older people even when adjusted for the other studied variables. However, in this population poor self rated health showed an inverse relationship with increasing frailty levels. Most studies done on self rated health as a determinant of frailty show that frail older people tend to

rate their health status as poor (Mello et al., 2014) or vice versa (Ocampo-Chaparro et al., 2013). Interestingly, a study done by Lucicesare et al. (2010) found that poor scores of self rated health did not increase mortality risk among the frail; instead poor scores showed an association to fit older people which lends support to the findings of this study. This does suggest that there may well be factors other than frailty that influences perception of one's own health. Understanding the cultural background of these older people and the social support available to them may shed some light on the directionality of the association in this study. These findings also suggest that measuring the self rated health changes alone as an outcome for intervention may not provide the intended result.

Any episode that impairs the stability of an individual required to maintain the intricate mechanism of balance can lead to falls and this risk is increased among the older people (Soriano, DeCherrie, & Thomas, 2007). The Frailty index (FI) of deficit accumulation has been associated with increased risk of falls among women (G. Li et al., 2014) and among those equal and above the age of 75 (O. J. de Vries, Peeters, Lips, & Deeg, 2013). The prior history of falls among older people has shown a strong association to frailty measured by both tools. The study findings support previous work on frailty which has shown similar associations between frailty and falls (Nowak & Hubbard, 2009). While frailty and falls show an association in this study one cannot make an assumption on the directionality of this association. Those with a history of fall are more likely to have some form of disability leading to higher frailty scores.

Falls as a predictor for frailty is much more apparent in studies done using the phenotypic definition of frailty as the domains are very specific to muscular strength, balance, coordination and disability. Most of the studies that measure physical parameters focus on sarcopenia; a term utilized to define loss of muscle mass and

strength that occurs with ageing and this condition is believed to play a major role in the pathogenesis of frailty (J. E. Morley et al., 2001). Frail subjects have almost five times higher risk of fall than robust older people in Korea (Shim et al., 2011) as compared to this population who have only two times or 4.6 times the risk using either the phenotypic definition or multidimensional definition respectively .

Another frailty indicator that is significantly associated with frailty is walking/gait speed. This study reveals that a slow walking/gait speed in the timed up and go test (based on cut-offs for the lowest 20th percentile for height) was significantly associated with being frail. Mean gait speed in a pooled analysis of nine cohort studies was 0.92 m/s (range 0.4m/s to 1.4m/s) much higher than the mean gait speed in this study which was 0.38m/s for men and 0.34m/s for women respectively (Studenski et al., 2011). This difference could be due to height differences between the Asian and African American and Hispanic population. Using cut points of 0.65m/s (L. P. Fried et al., 2001) found 50 percent of the population studied frail. Here, with gender stratified cut-offs described above 3.1 percent of the population was frail using the phenotypic definition.

The multidimensional Frailty Index definition found 6.9 percent of them frail using the same cut-offs. This study found that it was 6.2 times more likely to have abnormal walking speed than normal speed with increasing frailty levels. The relationship between slower gait speeds increasing the risk of fall among older community-dwelling older adults was described in the Einstein Aging Study (Verghese, Holtzer, Lipton, & Wang, 2009). One study suggests that interventions to increase and improve gait speed among older people may decrease the risk of frailty (Verghese et al., 2009). Gait speed when used as a single marker for frailty has also been shown to be a strong predictor of morbidity and mortality (Purser et al., 2006).

Apart from gait speed, abnormal grip strength showed a correlation to increasing levels of frailty. H. Syddall et al. (2003) investigated the role of grip strength as a single marker of frailty and found a strong association between the two variables. Grip strength has been a strong predictor of frailty in several other populations (Bohannon, 2008; Boyd et al., 2005) and was a significant predictor of frailty in this population.

The mean (SD) grip strength among the men and women in this study was 25.27 (8.9) kg and 15.11 (7.3) kg respectively. The Women's Health and Aging Study (WHAS II) had much higher mean scores which was 26.5kg (Q. Xue, Walston, Fried, & Beamer, 2011). The mean scores in this study was much closer to levels obtained in a hospital cohort study in Mexico City (19.53 (SD8.85) in men and 12.64 (SD5.98) in women (García-Peña et al., 2013). The chance to have abnormal scores in grip strength was 1.7 times more than normal scores with increasing frailty levels. Many epidemiological studies have demonstrated that low grip strength not only increases the risk of functional limitation and disability but in the older people it almost implies a loss of independence hence its role in predicting frailty warrants exploration (Norman, Stobäus, Gonzalez, Schulzke, & Pirlich). This proxy measure of upper body strength, lower body strength and the history of fall seem to be strong predictors for frailty and need to be explored further in our population.

Co-morbidities have been shown to be a strong determinant of frailty status in some studies (Blyth et al., 2008; Weiss, 2011). As early as 2004, in a review by Fried et al it was discussed that although the terms co-morbidity and frailty have a tendency to be used interchangeably they are distinct clinical entities that have unique challenges in management of frail older people (L. P. Fried et al., 2004). More recently, a cross sectional study involving 740 community dwelling seniors in Montreal found that among those who were classified as frail 81.8 percent had co-morbidities (Wong et al.,

2010). The moderating role of multi-morbidity in frailty and healthcare utilization is an interesting finding (van Oostrom et al., 2014) and with the expected rise in chronic diseases among older adults, extensive health resources are needed in the coming decades. A cross sectional study involving community dwelling older people in Spain found that co-morbidity was significantly associated with frailty with an odds ratio (OR) of 5.2 (Jürschik et al., 2012) However, this study did not find any significant association between the two variables.

The accumulation of deficit model has a further dilemma faced by researchers as the cut-off points to use to categorize the frailty levels differ. Song, Mitnitski, and Rockwood (2010) who were the pioneers in the accumulation of deficit model have proposed the cut-offs to be based on deviations from the mean; for example in this study the cut-offs FI≤0.08 as 'non-frail', FI≥0.25 as 'frail' and the rest in between as 'pre-frail'. Some of the papers have defined their frailty levels using the multidimensional model but the derived cut-off points used have not been described (N. M. de Vries et al., 2011; Drubbel et al., 2014). We do have other authors who explored the idea of having cut-off values that took age into consideration given the fact FI is known to increase exponentially with age (R. Romero-Ortuno, 2013). Now, though this idea seems the logical way to approach the definition of frailty, the trade off between benefit versus harm to the individual or group at large is a crucial decision.

The frailty phenotype criterion too has its fair share of variations. Most authors while maintaining the main construct in the cycle of frailty proposed by Fried and her colleagues has been adapted differently by various authors (Macklai, Spagnoli, Junod, & Santos-Eggimann, 2013; Roman Romero-Ortuno, 2013). However, the scoring method to categorize the three frailty levels have has been maintained due to ease in replication. A systematic review by N. M. de Vries et al. (2011) described an exhaustive

account of the various available frailty instruments available in current literature and its content. They found that a substantial part of all instruments concentrate on physical aspects of frailty especially nutritional status and mobility which are concepts correlating with Frailty Phenotype criteria.

The strength of this study is that two frailty assessment tools (based on two different definitions) were used to assess frailty and its correlates. Defining frailty largely depends on the operationalization of the concept whether using the accumulation of deficit model or the frailty phenotype criteria which are the two commonest models of frailty known today. What we have seen is that the models have been described in many ways that it is difficult to discern a specific fixed way of measuring frailty. The multidimensional frailty construct allows us to understand that being frail is not limited to physical abilities and strength, but may include psychological parameters, signs and symptom of ill health, hearing or visual attributes which contribute to the older person's risk of frailty. The physical measure of frailty allows us to test the role of co-morbidities and functional limitation as a risk factor of frailty. Each tool has its own strength in providing valuable information in the diagnosis and management of frail individuals.

Though measuring frailty using two tools has its pros, the limitation to this would be during decision making process on policy changes and resource allocation. There is a wide difference in the frailty percentages in the same population measured by both tools.

The repeated lower prevalence in levels of frailty using the Frailty Phenotype is probably that the Frailty Phenotype tool measures only the physical aspect of disability in an individual whereas the Frailty Index considers other domains such as psychological, physiological and co-morbidities. The different prevalence levels of

frailty using different tools raises the concern of which prevalence estimate accurately represents the condition in the population. Cesari et al. (2014) explained that while the decision on which tool to use relies heavily on the researcher and the school of thought they conform to, they do stress that the two tools are not substitutable or alternatives but rather complementary. This perspective may seem acceptable when seen from a clinical perspective as identifying the condition of frailty in older people takes precedence among all other concerns. However, when the perspective of a policy maker is taken into consideration it makes it rather difficult to decide on allocation of resources with large differences in the prevalence of frailty. In the light of this predicament, Martin and Brighton (2008) suggested in an editorial that for planning health services and application of health preventive applications, predictive ability of a tool may suffice.

Although, some authors have discussed the pros and cons of using both tools there is still no consensus on the most appropriate screening tool (Martin & Brighton, 2008; Moorhouse & Rockwood, 2012). Hence, identifying the screening tool that can provide the best predictive validity to the issue of interest to the policy makers is likely the best way forward for now.

We now know the burden of frailty in Malaysia and the various factors that influence the complexity of this condition. With high levels of disease burden among the frail, the health system needs to be able to provide for their needs and demands. To address this need among the frail older people and the gaps that needs to be filled in our healthcare system, analysing the patterns of healthcare utilization among the pre-frail and frail older people is essential. This perspective will be discussed in Chapter 7.

CHAPTER 7 FRAILTY AND ITS ASSOCIATION TO HEALTH SEEKING PATTERNS

7.1 Introduction

People are living longer than before, which is one of the greatest achievements of mankind. The challenges that made this phenomenon a reality does come with its fair share of consequences. The longer we live the greater the need for sustainability, support system, finances, targeted policies, radical infrastructural changes, and most of all changes in cultural and mental adaptation.

Understanding the patterns of utilization of healthcare services among the older people especially those who are pre-frail or frail will give an insight on the preparation and changes needed to be made to provide precise and quality services that will be optimally utilized and beneficial to both the older people and the society in general.

This chapter will provide an understanding on healthcare utilization patterns among the older people in Malaysia especially those who are pre-frail and frail. Section 7.2 will describe the global burden of disease we have today and an overview of healthcare utilization patterns that is seen among the older people. In Section 7.3 a description of several health services utilization models is given followed by Section 7.4 explaining the various factors that influence healthcare utilization patterns in an individual. Section 7.5 engages in a discussion on frailty and its association to healthcare utilization. The methodology and conceptual framework used to answer the objective of frailty and its association to patterns of healthcare utilization will be described in Section 7.6. Section7.7 will present the results obtained in this research. This section will be followed by Sections 7.8 which will be a summary on the findings.

7.2 Global burden of disease and healthcare utilization among the older people

A vital part of this change in ageing trends is the need for better healthcare services to maintain the longer lifespan in its optimum state, and to keep morbidity and mortality at bay. There is a rising prevalence of global health concerns among older adults and the older people mainly in chronic non-communicable diseases such as heart disease, hypertension, diabetes, and cancer (World Health Organization, 2011). The Global Burden of Disease 2004 update reported that the leading contributors to disease burden in older people are cardiovascular diseases (30·3 percent of the total burden in people aged 60 years and older), malignant neoplasms (15·1 percent), chronic respiratory diseases (9·5 percent), musculoskeletal diseases (7·5 percent), and neurological and mental disorders (6·6 percent) (M. J. Prince et al., 2015). As evidenced in Figure 7.1, a result of the multi-country Global Burden of Disease project, research shows that over the next 15 years people in every region will suffer more death and disability from non-communicable diseases regardless of income level (Mathers & Loncar, 2006). This clearly refutes the myth that non-communicable diseases mainly afflicted the more affluent populations in the world.

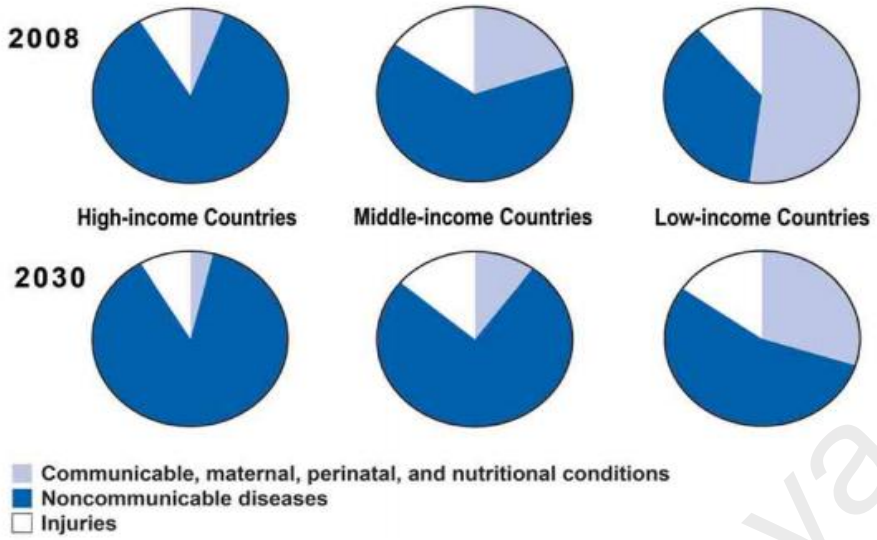

Figure 7.1 The Increasing Burden of Chronic Non-Communicable Diseases: 2008 and 2030 (Source: World Health Organization, Projections of Mortality and Burden of Disease, 2004-2030.)

The prevalence of musculoskeletal conditions increases markedly with age and it was recognized in a report by Woolf and Pfleger (2013) that in most countries, 10-20 percent of primary care consultations arose from musculoskeletal complaints. The Korean Longitudinal Study of Ageing (KLoSA) found that depression was prevalent among the older population in South Korea and this together with the existence of chronic medical illness led to an increased level of healthcare utilization than those diagnosed with only depression (Kim, Park, Jang, & Kwon, 2011). Data from the World Health Organization Study on Global AGEing and Adult Health (SAGE) involving six low and middle income countries, found that the older people in the 70 to 79 age group were 20 percent more likely to use outpatient services than adults in the 50 to 59 age group (Peltzer et al., 2014). The report also found that women were more likely to use outpatient services as compared to men and those with multi-morbidity tended to use more inpatient and outpatient services as compared to those with no reported chronic disease.

The projected increase in the non-communicable disease in the ageing population suggests a substantial cost burden to the healthcare system in this era of escalating

medical costs (Y. C. Wang, McPherson, Marsh, Gortmaker, & Brown, 2011). An analysis by the World Health Organization on 23 low and middle income countries estimated the economic losses from three non-communicable diseases (heart disease, stroke and diabetes) in these countries would be USD83 billion in a span of 10 years (World Health Organization, 2011). The literature review done by Lehnert et al. (2011) to investigate the relationship between multiple chronic conditions and healthcare utilization summarized that not only did the two factors have a positive association with one another but a near exponential relationship was observed between multiple chronic conditions and costs. Apart from chronic non-communicable diseases, falls are almost always an incident finding of ageing. Fall related injuries have been associated with substantial economic costs especially among older women aged 65 and above (Stevens, Corso, Finkelstein, & Miller, 2006). The study done by Stevens et al. (2006) also projected that by 2013 direct medical costs for injuries due to falls in older adults, adjusted for inflation would be approximately USD34 billion and this large sum still does not cover costs incurred due to long term effects such as disability, dependence on a caregiver, lost time from work and household duties, and quality of life. In most countries, policymakers and stakeholders are starting to recognize this problem and are arduously trying to develop a safety net to protect these older people from the impact of high healthcare costs. This becomes a daunting feat to accomplish in countries that do provide universal health coverage.

7.2.1 Burden of disease and healthcare utilization among the older people in Malaysia

Even though Malaysia does not have a high percentage of older people currently as compared to some ageing nations like Japan and Singapore, with the fertility and life span trends that are changing, we too will share that ageing demographic profile soon.

The older people in Malaysia have their fair share of disease burden and these have become a concern for any individual involved in work surrounding older people health and well-being.

Figure 7.2 depicts the top disease burden as measured in DALYs for persons aged 60 and above in Malaysia. In 2004, cardiovascular diseases, sense organ diseases and malignancies account for the top three commonest afflictions among the older people. The report by the Western Pacific Regional Office of the WHO also states that 87 percent of the disease burden was made up of non-communicable disease and 11 percent communicable and nutritional conditions and this pattern will continue till 2030 (World Health Organization, 2013).

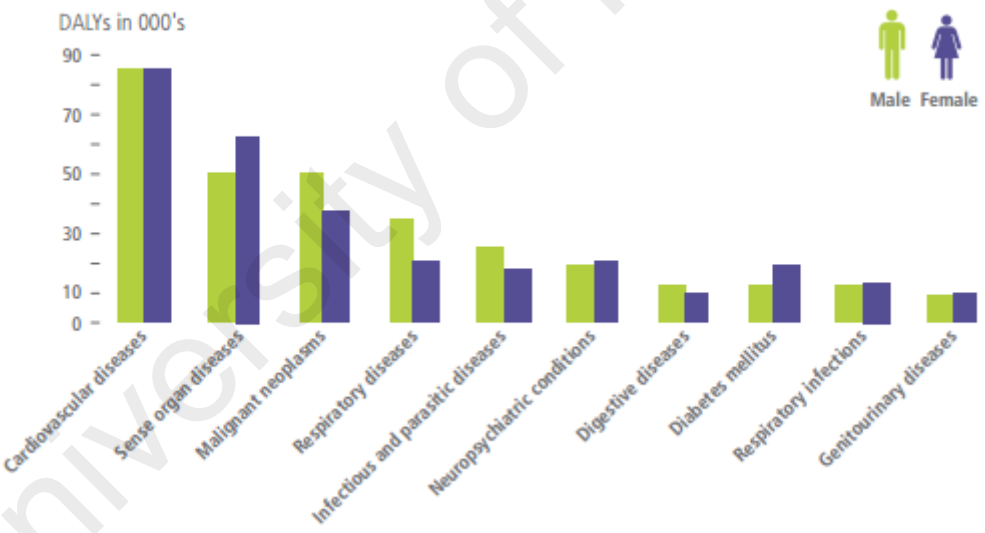

Figure 7.2 Top disease burdens (DALYs) for persons aged 60 years and above, by sex and disease subgroups, Malaysia, 2004
(Source: Western Pacific Regional Office, 2004)

A study done by A. Rashid, Manan, and Rohana (2010) highlighted 30.1 percent of older Malays in rural Malaysia suffered from depression and a proportion of them required consultation with a health professional ranging from general practice to specialized care. Another study found that the prevalence of hypertension among the older Malays was 54.5 percent (A. K. Rashid & Azizah, 2011). The older people in

Malaysia performed poorly in a glycaemia control study where 74 percent of them had poor glycaemia control (Akmal, Zaitun, Zaiton, & Salmiah, 2011). From the data obtained in the Malaysian National Health Morbidity Survey III (2006) higher utilization of healthcare services was found among women with diabetes and those diagnosed and living in rural areas (Letchumanan et al., 2010). However, the data for the older population is still limited. Findings from Chapter 6 support the fact that frailty is prevalent among the older people in Malaysia as found by other researchers (Sathasivam, Kamaruzzaman, Hairi, Wan, & Chinna, 2015) however we do lack data on healthcare utilization patterns among frail older people.

Malaysia has a dual tiered healthcare system: a synergistic public-private healthcare system. The public-private share of outpatient utilization in Malaysia is about 50:50 (Chen C.M., 2011). It was reported by the National Clinical Research Centre (2015) that 71 percent of the total hospital admissions in 2013 were in the public sector where the public sector experienced a 2.5 times more admissions per day than private hospitals. An analysis into the outpatient care services among Malaysians showed that those with lower socio-economic status tend to favour the public healthcare services than the private healthcare services and there is an increasing tendency for those with higher economic status to use private care (Jabrullah A.H. et al., 2014).

As evidenced in the sections earlier, we do know that the burden of chronic disease in Malaysia is high. Ramli and Taher (2008) found that most Malaysians who were aware of their chronic disease status receive care primarily at the government sector citing high costs of long term treatment in the private and the absence of an organized funding system are likely to be the reason for their choice of treatment provider. The expense of utilizing health services at private facilities is higher than at public facilities (H. T. Chua & J. C. Cheah, 2012). Access to private health services is inevitably limited to the richer segments of the population that can afford to pay high user fees as out-of pocket

payments or co-payments (with coverage of private insurance) (C. P. Yu, Whynes, & Sach, 2008). The World Health Organization reported that from 2010-2013, Malaysia spent four percent of her gross domestic product (GDP) on healthcare (World Health Organization, 2014a). With rising healthcare cost seen globally, the government may need to cut back on their subsidies and this will require the people to start paying out of pocket especially for those who do not have any insurance backing (The Economist, 2014). Studies have shown that cost of care for older people makes up a large part of total healthcare expenditure and this has led to rationing of care for the older people (Brockmann, 2002). The sustainability of the healthcare system does require scrutiny with the shifting proportion of older population and rising percentages of non-communicable diseases.

The older person with their deteriorating health status would place a high burden on this expenditure leading to an increase in the future as the ageing demography increases in Malaysia. Apart from non-communicable diseases, we know conditions common to older people such as falls, musculoskeletal diseases, neuro-psychiatric conditions such as depression and Alzheimer's contribute to this increased health costs. Frailty being a syndrome which has most of these ageing conditions as part of its spectrum would likely amplify the need for health services and increase the costs. The literature on specific patterns of healthcare utilization for frail patients is scarce but to contain escalating health expenditures involving the older people is a perspective that needs to be addressed. This chapter attempts to understand the patterns of healthcare utilization among the older people in Malaysia especially those who are frail to help us identify factors that contribute to the increased utilization.

7.3 Behavioral models associated with healthcare utilization

As early as 1973, Avedis Donabedian defined health services utilization as: "multidimensional process is determined by the outcome of the interaction between health professional and patients" (Da Silva, Contandriopoulos, Pineault, & Tousignant, 2011). To understand which determinants directly affect healthcare utilization is difficult but is certainly influenced by knowledge, culture, perception, economic conditions, age, social strata and access to services among others (Rebhan, 2008). Rebhan (2008) further describes three models of health services utilization; Rosenstock's Health Belief Model, Anderson's Health Behaviour Model and Young's Choice Making Model which serve as platforms for predicting health related behaviours. Rosenstock's Health Belief Model, one of the first theories of health models developed by social psychologists was introduced in the early 1950s. Despite the model being created to explain the failure of programmes, particularly tuberculosis by the United States Public Health Service, it highlighted an important concept that influenced health behaviour which was perception whether in terms of seriousness (perception of the consequence of the health condition), susceptibility (perceived risk of contracting the health condition), benefit (the understanding on the advantages of specific behaviours) or barriers (difficulties or cost for changing certain behaviours) (Rosenstock, Strecher, & Becker, 1988). Later it was identified that this model had two other influencing factors which was the self confidence in an individual to take the behavioural change and the exposure to the factors that prompt that change (Orji, Vassileva, & Mandryk, 2012).

The Health Belief Model explained most of the behavioural changes in health services utilization in the early years until a conceptual model known as the 'Anderson's Health Behaviour Model' to explain factors leading to health care utilization was developed by Ronald M. Anderson in 1968. First there are predisposing characteristics in an

individual such as their demographic profiles, the social structure that they come from and their personal inherent beliefs. Some demographic profiles such as age and gender are biological imperatives that will likely lead them to use health services. However, social structure usually measured by cultural norms, ethnicity, marital status, education and income will determine the ability of an individual to cope with presenting health issues and influence their health beliefs (Anderson, 1995). The model also stresses on perceived need which is influenced by the health belief, social structure and their subsequent use of health services. The Anderson Model is useful to study the outcomes of healthcare utilization due to its flexibility in the independent variables that can fit into the predisposing, enabling and needs domains. Therefore, this model allows the determination of patterns of utilization among different groups to highlight inequalities (Willis, Glaser, & Price, 2010).

The third model that warrants highlight is Young's Choice Making Model which was based on ethnographic studies of health services utilization in Mexico (Young ✠, 1981). This model is deep rooted in the basic culture of the studied population. The model has four basic components each deeply embedded in the web of faith and culture which are gravity of illness (the individual and social perception of the severity of the illness), knowledge of home remedy (the likely option prior to considering allopathic services), faith in the treatment (the belief in the efficacy of the treatment) and the accessibility (personal evaluation of health access and cost) (Rebhan, 2008). In a multi-ethnic society such as Malaysia, the Young's Choice Making Model does have a significant role however it becomes a complex model to decipher with inter-racial and intercultural families that make up the population here. The clear-cut delineation as to one's cultural belief is becoming rather grey as the years have passed.

A systematic review highlighted that most healthcare utilization measurements include environmental variables which encompass the delivery system, external environment

and community-level enablers or provider related variables which include patient-provider interaction (Phillips, Morrison, Andersen, & Aday, 1998). More recently, Da Silva et al. (2011) proposed that assessing health services utilization can be from the patient or the physician perspective. The patients perspective usually covers accessibility based on logistic and finances, continuity based on trust, coordination of care as provided by the main provider (Haggerty et al., 2008) and the physicians angle would include continuity of service, comprehensiveness and accessibility which indicate quality of the service (Da Silva et al., 2011).

Another systematic review concurs that while no gold standard is available to date, self report measures which are often used to estimate healthcare utilization reveal variable accuracy (Bhandari & Wagner, 2006). These authors do however, conclude that in self-report measures hospitalization data seems more accurate as it stands out in memory during recall and the acceptable time frame for recall should be limited from six to 12 months. What we have to date are various health services assessment tools or instruments which range from extracting data from health financing databases such as Medicare or Medicaid (Moon & Shin, 2006) or creating specifically designed questionnaire based on a framework to answer the intended objectives (Rochat et al., 2010; Schweikert, Hahmann, & Leidl, 2008). Measuring healthcare utilization relies highly relies on what the investigator wants to understand or discover or the research framework used.

7.4 Factors influencing healthcare utilization

7.4.1 Demographic characteristics

In the ongoing debate on factors that influence healthcare utilization, demographic characteristics have been cited as an important determinant. Gender differences primarily women have been found to have higher medical care service utilization and in

turn higher associated expenditures (Bertakis, Azari, Helms, Callahan, & Robbins, 2000). The potential determinants that caused these gender differences were found to be number of chronic diseases and health related quality of life in one study (Redondo-Sendino, Guallar-Castillon, Banegas, & Rodriguez-Artalejo, 2006). The reason for utilization rate differences has not been uniform across countries as evidenced by work done by Schenck-Gustaffson, DeCola, Pfaff, and Pisetsky (2012). They found that in high-income countries the usage may be more due to engaging in preventive health activities and in emerging economic countries there may be restrictive barriers such as familial and financial commitments. Apart from gender, age and marital status are also factors that influence the healthcare utilization patterns. Age differences were seen in younger age groups mostly among the working population for maternity care (Cylus, Hartman, Washington, Andrews, & Catlin, 2010) and more utilization among the old-old for end of life care (Bird, Shugarman, & Lynn, 2002). The Irish Longitudinal Study on Ageing (TILDA) found that though age was not a key driver for the use of medical care, older people tend to use more than younger people (McNamara, Normand, & Whelan, 2013). This study also found that married individuals have longer hospitalization probably because the unmarried people are discharged to institutional care. Factors such as age or marital status were seen to be strong determinants in healthcare utilization among 1312 Swedish men and women (Ahmad, Dag, & Kurt, 2004).

7.4.2 Social status

Income and education play a salient role in determining the socio-economic status of an individual and a clear understanding of this has implications on policies and resource allocation. A study involving 2116 Nova Scotians showed that individual income and the level of education both play an important role in physician and hospital use (Yip,

Kephart, & Veugelers, 2002). In Greece, income was seen to affect utilization of primary healthcare but only in the lower income levels (Geitona, Zavras, & Kyriopoulos, 2007).

An important perspective that has been found to be a barrier among socioeconomically vulnerable populations is the lack of health insurance which prevents one from using health services (Scheppers, van Dongen, Dekker, Geertzen, & Dekker, 2006). Having some form of medical plan or health insurance makes a difference in the utilization of healthcare as seen in the study done by Finkelstein et al. (2012) which found that low income adults having Medicaid had higher preventive and primary care use and increased hospitalization as compared to similar income individuals without a health insurance plan.

Adler and Newman (2002) recommend that reducing socio-economic disparities will in turn reduce health disparities, whether in terms of morbidity and mortality or the ability to access and utilize.

7.4.3 Health Beliefs

Culture is a complex term which influences values, health beliefs, practices and meaning usually transmitted through a process of enculturation (Rebhan, 2008). Western industrialized societies view diseases as a natural scientific phenomenon where sophisticated medical technology is the most likely answer to treat and diagnose diseases, whereas we have a myriad of societies that do not conform to such ideologies. Asians, Native Americans, Africans and such societies have a distinct perception on health and disease and health practices that are significantly different from their industrialized counterparts. Understanding the belief system of these cultural communities globally is an arduous task as it can be an intermingling of spiritual factors, generational stigmas, familial beliefs, astronomy, cosmology and internal body

energy to name a few. In a review done by Scheppers et al. (2006) it was found that many studies found that differences in health belief does have an impact and acts as a barrier to health care. However, these studies were mostly confined to ethnic minorities arising from migrant populations in Western societies. One study refuted the speculation that these traditional beliefs are an important barrier to access and utilize healthcare services (Jenkins, Le, McPhee, Stewart, & Ha, 1996). What may be difficult to distinguish is if the intent to utilize the available health services is influenced negatively by the health belief which may be viewed as archaic or the positive outcomes that they have witnessed over time solely believing in the supernatural or natural causes.

7.4.4 Perceived Needs

One of the most important variables that play a role in utilizing inpatient or outpatient healthcare services is the perceived needs. Needs are classified as direct needs, indirect needs and unmet needs based on the essence they are derived from. Direct needs arise due to pre-existing illnesses or sustained injury that a person has to obtain the care and treatment that they deserve in order to facilitate cure or at the least control. Indirect needs are to utilize the existing services to enhance their current status of health even when they are healthy; for example to obtain vitamins and supplementation, general health check-ups, screening or diagnostic tests, blood donations and maintaining dental and personal health. The indirect needs are usually determined by the trends on utilization patterns available over the years and the ability to utilize healthcare services incorporates affordability, accessibility, availability, cultural norms and social networks. It as been shown that in health services planning, obtaining information from survey data ar previous utilization data, policymakers are able to obtain information about populations requiring different levels and types of services (Goldsmith H.F., Bell, & Warheit, 1992). If this web of necessities to enable healthcare utilization is not readily

paved then there will be an unmet need for health care. Unmet healthcare needs are the difference between the healthcare services deemed necessary to deal with a particular health problem and the actual services received. Studies dealing with elderly with specific diseases often focus on poor home care and lack of assistance in activities of daily living (Herr, Arvieu, Aegerter, Robine, & Ankri, 2014). It is known that older people often have more complex needs due to additional disability, physical and social needs and disparities in accessibility and affordability can cause substantial differences in health outcomes.

Even though there are various models that can be mapped to understand patterns of healthcare utilization the objective that is posed in this study can best be addressed based on the needs to utilize the services and the demographic profiles that influence that need using the Anderson's Health Behaviour Model (see Figure 7.3). Older people in a frail state will have specific needs from the healthcare system due to the combination of health issues they have. The socio-demographic status and economic profiles can further influence this need. Cultural differences in Malaysia influencing their health beliefs and utilization patterns are perspectives that have to be considered when choosing a model. This model is chosen for this research as this model best describes the factors that influence utilization of health services by older people Malaysians who are frail.

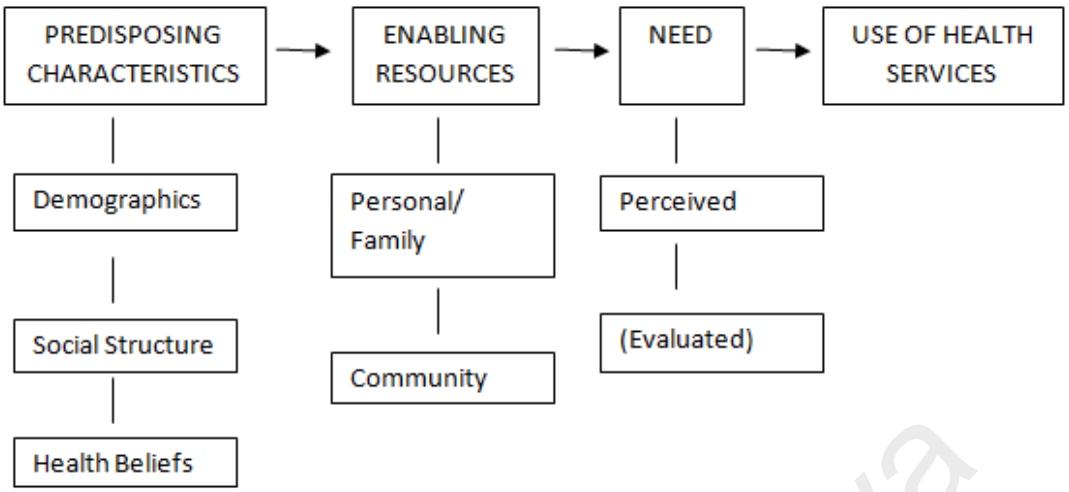

Figure 7.3 Health Behavioural Model (Anderson, 1995)

7.5 Frailty and healthcare utilization

What we know is that there are many factors that fit into the healthcare utilization model which will influence the patterns of healthcare utilization among the older people. One of the inevitable findings among most older people is their status of frailty and how this subgroup of older people use the healthcare services and their needs may help us formulate better policies and services for them. Frailty has been repeatedly associated with increased utilization of healthcare (Boyd et al., 2005; R. J. J. Gobbens & van Assen, 2012; Hoeck et al., 2012; Martine T. E. Puts, Shekary, Widdershoven, Heldens, & Deeg, 2009). Healthcare utilization was operationalized by R. J. J. Gobbens and van Assen (2012) using six indicators: visits to a general practitioner, contacts with healthcare professionals, receiving personal care, receiving nursing care, receiving informal care and admissions to a hospital in a self-report questionnaire..

In the evidence table (Table 7.1) below, four population based studies (R. J. J. Gobbens & van Assen, 2012; Hoeck et al., 2012; Rochat, Cumming, Blyth, Creasey, et al., 2010) showed strong associations of frail older people and increased odds of visits to general practitioners, specialists, emergency department and hospitalization as compared to those not frail. The study done by Douglas P. Kiel, Patricia O'Sullivan, Teno, and

Vincent Mor (1991) highlighted that repeated fallers; a common feature of frail older people were at higher risk for healthcare utilization.

Table 7.1 Frailty and patterns of healthcare utilization

Author and Title	Study Design	Participants	Findings
Rochat S. et.al. (2010) Frailty and use of health and community services by community dwelling older men: CHAMP study	Population based study: cohort	Men aged 70 years and above	Frailty strongly associated with use of health and community services (OR 2.04)
Hoeck S et.al. (2011) Healthcare and homecare utilization among frail older people in Belgium	Cross-sectional study : population based	4777 older people >65 years	Frailty was associated with higher GP visits (OR 4.35), specialist visits (OR 1.75), emergency department (OR 6.20), hospital admission (OR2.67)
Kiel DP. Et.al. (1991) Healthcare utilization and functional status in the aged following a fall	Longitudinal cohort: Population based study	11,497 Non-institutionalized older people >65 years	Females were higher fallers Hospitalization (1 time fallers 1.36) (>1 time 1.57) Physician contact (1 time fallers 1.28) (>1time 1.48) Nursing home admission (1 time fallers 2.65)(>1 time3.48)
Gobbens RJ et.al. (Frailty and its prediction of disability and health care utilization: the added value of interviews and physical measures following self-report questionnaire	Prospective cohort population based study	245 older people community dwelling	Increased visits to a general practitioner (gp), contacts with health care professionals (hcps), hospital admission, receiving personal care, receiving nursing care, and receiving informal care.

gp = general practitioner

In Taiwan, (L. F. Liu, Tian, & Yao, 2012) found that the likelihood of increased utilization and expenditure increased with age, frailty status and co-morbidities. Bhandari and Wagner (2006) summarized in a review that to date there is no gold standard in self-reported measures to assess utilization of healthcare. Principles that need to be considered when measuring healthcare utilization are period of recall, type of

utilization, question design and the use of continuous outcome measures (Bhandari & Wagner, 2006; Petrou, Murray, Cooper, & Davidson, 2002).

Most authors agree that targeting resources and preventive measures to frail older population can reduce their number of visits to a healthcare personnel or admissions to a hospital (Boyd et al., 2005; S.E. Espinoza & Fried, 2007; Mohandas et al., 2011; Robinson, Wu, Stiegmann, & Moss, 2011).

7.6 Methodology

The data was collected from every older respondent as described in Chapter 4 and as part of the interview based questionnaire, the healthcare utilization component was administered for every older person which gave rise to 789 study participants in total. The response rate for the healthcare utilization was 100 percent. Each section was checked thoroughly before leaving the household to minimize missing data. English and Bahasa Malaysia Coding Booklets (Appendix E) were available to select the answer options for Section A to D that was provided by the respondents and to enable the older person to choose an option that best suited their reason. The NHMS II questionnaire has been validated a priori in the Malaysian population (including all ages) hence was not revalidated in this study.

7.6.1 Study Instrument

a) Healthcare utilization pattern was measured by a set of questions adapted from the National Health and Morbidity Survey II (NHMS II) in which Part A and Part B had 2 broad screening questions:

i. *In the last 2 weeks, from _____ till today did you experience any injury or suffer from any health problems?*

ii. *In the last 2 weeks from _____till now, did you receive any outpatient care?*

If the respondent answered yes to both global questions, then a series of questions regarding their reason for use, choice of healthcare provider, number of visits and the direct payment made per visit were asked as listed in Part B. If the respondent had answered yes to the first question but did not receive outpatient care, they would then be administered questions in Part C which would highlight the reasons for not receiving care, if they had decided to self-medicate or use alternative treatment measures and the amount they spent to self treat or obtain that treatment. If they had answered no to the first broad screening question, the respondent then proceeded to answer questions listed

in Part D which covered reasons for utilizing outpatient services despite not needing it. Following that, every respondent was required to answer Part E which assessed patterns of inpatient utilization. Inpatient utilization was assessed by a single question;

In the last 12 months from _____till now, have you been admitted to any hospital?

For respondents who answered yes, they will then have to answer four more questions regarding the place of hospitalization (public or private), number of admissions, days of stay and total amount spent for each admission (Part E, Appendix C).

The recall period for outpatient utilization was two weeks and for inpatient utilization was one year. In has been recommended from the World Bank Institute that for health services that have higher frequency of utilization, such as ambulatory care, the optimal recall period is in the range of two to four weeks and for inpatient care should be longer, typically 12 months (O' Donnell, van Doorslaer, Wagstaff, & Lindelow, 2008). The information provided regarding outpatient or inpatient use was confirmed using their outpatient card or discharge summary if available. The socio-demographic and socio-economic details are obtained to fulfil the predisposing characteristics of the model.

b) Frailty was assessed using the Frailty Phenotype classification (described in Chapter 4, Section 4.6) because this tool has better predictive validity to examine short term adverse outcomes of frailty and as described in Chapter 5, Section 5.9.

7.6.2 Conceptual Framework

The objective set to answer the patterns of healthcare utilization by these study respondents is best depicted in the conceptual framework given below (Figure 7.4) (covering the enabling and needs factor in Andersons Behavioural Model given in Figure 7.3). The first subgroup identified in this research is if anyone had experienced

an injury or illness in the preceding two weeks of the interview. Those who did have an experience will be categorized into two further groups; Group 1 representing those who utilized outpatient services and Group 2 for those who did not. Group 3 represents the older people who were not ill or injured in the preceding two weeks but had to utilize outpatient services. Each group will have a series of questions which will give further descriptions on their patterns of utilization.

		Utilized outpatient services?	
		Yes	No
Injured/ Ill in the last 2 weeks?	Yes	(Part B:DIRECT NEEDS) Q1-received outpatient care Q2- no of facilities visited Q3- type of facilities visited Q4- How much money spent on each visit	(Part C: UNMET NEEDS) Q1- reason for not seeking treatment Q2- Was self-medication practised? Q3- How much spent on self-medication?
	No	(Part D:INDIRECT NEEDS) Q1-not ill but used services...reason? Q2- Type of facility used? Q3- no of visits to these facilities? Q4- How much spent on each visit?	Not tested

Q =question

Figure 7.4 Conceptual framework of patterns of outpatient healthcare utilization (NHMS2)

7.6.3 Operational Definition of Terms

Table 7.2 Operational definition of terminologies for frailty and healthcare utilization

Healthcare services	Operational Definition
Inpatient care	This means staying at any place to get care which requires at least an overnight stay. The places include hospitals, clinics, traditional practitioners centre/home.
Outpatient care	This means care that does not involve admission to ward. Home visits by any healthcare provider, day visits to emergency department and any care obtained from day-care/ambulatory care centres was included.
Healthcare provider	Includes clinics, clinics in a hospital, emergency department, day care or ambulatory care centre, pharmacy, traditional practitioners such as 'bomoh', 'sinseh', 'ayurvedic' and 'faith healers'.
Frailty Classification	Individuals were considered frail based on the phenotypic definition of frailty.[3] The choice of frailty tool to assess frailty in this population has been described earlier in Chapter 5, Section 5.8. Those with no positive finding from 5 predetermined parameters were considered robust, 1-2 positive findings was categorized as pre-frail and 3-5 positive findings classified as frail.

[3] Explanation for the use of Frailty Phenotype to measure association to healthcare utilization outcomes (Chapter 5, Section 5.8)

7.6.4 Data management and analysis

All the data was entered into IBM Statistical Package for Social Sciences (SPSS) Software Version 21.0 and coded as specified in the questionnaire given in Appendix C. The data was cleaned and coded to represent each item as described in Chapter 4, Section 4.11. There was no missing data. Data was analysed for each subgroup using descriptive statistics for complex samples. Results are presented in percentages (confidence interval: CI). As mentioned previously in Chapter 4 (Section 4.110, the results presented are population weighted.

7.7 Results of outpatient healthcare utilization

7.7.1 Direct need for outpatient services

Table 7.3 depicts the outpatient utilization patterns of the study respondents who have been involved with some form of injury or ill health in the two week duration prior to the study. Among the frail older people, 35.0 percent of them sustained or suffered from some form of illness or injury in the two weeks prior to the interview where as only 16.1 percent (95% CI 12.7, 20.3) who were pre-frail or 14.2 percent (95% CI 11.0, 18.2) who were robust had a need for outpatient services. There is a higher need for healthcare services among the frail as compared to the pre-frail and robust older people. However, despite the need for outpatient services increasing with the level of frailty, only 27.0 percent (95% CI 6.7, 65.5) of the frail older people who needed the service utilized the outpatient services as compared to 73.1 percent (95% CI 59.8, 83.1) pre-frail and 61.2 percent (95% CI 47.2, 73.5) robust older people who were ill or injured. The frail older people who needed the services more had lower utilization.

Public healthcare services was the only preferred outpatient service among the frail older people. However, both the robust and pre-frail groups chose public or private healthcare services with equal preference.

More than half frail older people (57.1 percent, 95% CI 7.7, 95.5) spent ≤RM50.00 during their first visit and 42.9 percent (95% CI 4.5, 72.3) of them had to spend more than RM100.00 for their treatment. The percentages of frail older people having to spend more than RM100.00 was very high as compared to 8.8 percent (95% CI 3.3, 21.4) and 3.0 percent (95% CI 0.4, 18.6) among the pre-frail and robust older people.

Table 7.3 Older people ill or injured in the last two weeks and utilized outpatient services by frailty status (Direct need)

No.	Item	Options	Robust % (95% CI)	Prefrail % (95% CI)	Frail % (95% CI)
1)	Have you had injury or illness in the past 2 weeks?	Yes	14.2 (11.0,18.2)	16.1 (12.7, 20.3)	35.0 (18.5, 56.1)
2)	Have you ever received outpatient care in the last 2 weeks?	Yes	61.2 (47.2, 73.5)	73.1 (59.8, 83.1)	27.0 (6.7, 65.5)
3)	How many health facilities did you visit for your problem?	1	89.2 (74.4, 95.9)	81.5 (67.7, 90.2)	100.0 (100.0, 100.0)
		2	10.8 (4.1, 25.6)	14.8 (7.1, 28.1)	-
		3	-	3.8 (0.9, 14.1)	-
4a)	Choice of facility as 1st treatment option	Govt Primary care	40.5 (20.8, 51.8)	45.6 (28.0, 56.9)	100.0 (100.0, 100.0)
		Public hospital	8.8 (2.8, 24.4)	6.8 (2.2, 19.2)	-
		PrivateGP/hospital	45.3 (29.7, 61.8)	42.8 (29.1, 69.2)	-
		Traditional	-	4.7 (1.2, 17.1)	-
		treatment	5.4 (1.3, 19.5)	-	-
		Pharmacy (OTC)			
4b)	Choice of facility as 2nd treatment option	Govt Primary care	51.7 (13.0, 88.4)	21.9 (5.4, 57.8)	-
		Public hospital	48.3 (3.5, 77.1)	44.9 (11.1, 67.3)	-
		PrivateGP/hospital	-	33.2 (10.9, 66.7)	-
		Traditional Rx	-	-	-
		Pharmacy (OTC)	-	-	-
5a)	No. of visits to 1st choice of facility	1 visit	100.0 (100.0, 100.0)	97.7 (85.6, 99.7)	100.0 (100.0, 100.0)
		2 visits	-	2.3 (0.3, 14.4)	-
5b)	No of visits to 2nd choice of facility	1 visit	100.0 (100.0, 100.0)	100.0 (100.0, 100.0)	-
		2 visits	-	-	-
6a)	Total expenditure on 1st visit	≤RM50	82.9 (66.7, 92.2)	74.4 (59.8, 85.1)	57.1 (7.7, 95.5)
		RM51-RM100	14.0 (5.9, 29.8)	16.8 (8.5, 30.5)	-
		>RM100	3.0 (0.4, 18.6)	8.8 (3.3, 21.4)	42.9 (4.5, 72.3)
6b)	Total expenditure at 2nd visit	≤RM50	100.0 (100.0, 100.0)	88.8 (49.5, 98.4)	-
		RM51-RM100		11.2 (1.6, 50.5)	-
		>RM100	-	-	
			-		

Results presented as percentage (confidence interval)

7.7.2 Unmet needs in outpatient services

There was a group of older respondents who had some form of injury of illness in the preceding two weeks of the interview but did not utilize the outpatient services (Table 7.4). Among the frail older people who had some injury or illness, 73.0 percent (95% CI 34.5, 93.3) of them did not utilize outpatient services. In the pre-frail and robust categories, 26.9 percent and 38.8 percent of them who were injured or ill did not use outpatient services respectively. It is now known from the literature in Chapter 6 that illness or injury can cause the older people to become frail and these older people will need healthcare support compared to healthy active older people so it is important to know the reason for this large percentage of underutilization among the frail older people.

Table 7.4 (item 3) shows the primary reason cited by the three categories of older people for not using the healthcare facilities despite needing it. Among frail older people who needed care but did not obtain such care 82.7 percent (95% CI 35.7, 97.6) indicated a lack of transportation as their main reason. However, the main reason cited by 40.3 percent of pre-frail older people and 32.4 percent of the robust older people was that their illness was not severe enough to warrant care.

It is estimated that 17.3 percent (95% CI 2.4, 64.3) of the frail older people who did not go to the healthcare facility opted to treat themselves either by using previously prescribed medications that was in stock at home or by using home-based remedies passed on by their ancestors. However, the proportion of robust older people who self-medicated was much higher at 73.2 percent (95% CI 50.8, 87.9).

Among the frail older people who self-medicated, 82.7 percent of them claimed that their efforts to self medicate was free. However, when the average expenditure for self medication increased to more than RM30.00, 17.3 percent of the frail older people (95%

CI 2.4, 64.3) had to fork out that amount as compared to only 11 percent among robust older people.

Table 7.4 Older people ill or injured in the last two weeks but did not utilize outpatient care services (Unmet needs)

No.	Item	Options	Robust	Prefrail	Frail
1)	Have you had injury or illness in the past 2 weeks?	Yes	14.2 (11.0,18.2)	16.1 (12.7, 20.3)	35.0 (18.5, 56.1)
2)	Have you ever received outpatient care in the last 2 weeks?	No	38.8 (26.5, 52.8)	26.9 (16.9, 40.2)	73.0 (34.5, 93.3)
3)	Reason for not using outpatient services	Illness not severe	32.4 (15.2, 56.3)	40.3 (19.3, 65.7)	17.3 (2.4, 64.3)
		Fear of medical treatment	12.4 (3.1, 38.1)	14.0 (3.5, 42.1)	-
		Fear of healthcare practitioner	5.6 (0.8, 31.0)	6.7 (0.9, 35.4)	-
		Fear of medical instruments	10.1 (2.5, 32.9)	5.7 (0.8, 31.4)	-
		Busy with chores	-	6.7 (0.9, 35.4)	-
		No transport	28.5(13.1, 51.5)	7.3 (1.0, 37.8)	82.7 (35.7,97.6)
		Procrastination	-	4.6 (0.6, 26.9)	-
		Believes will self-resolve	4.8 (0.7, 27.4)	-	-
		Unable to accept reality	-	7.3 (1.0, 37.7)	-
		Not much hope left	6.2 (0.9, 33.2)	7.3 (1.0, 37.7)	-
4)	Did you attempt to self-medicate?	Yes	73.2 (50.8, 87.9)	27.0 (10.5, 54.0)	17.3 (2.4, 64.3)
		No	26.8 (12.1, 49.2)	73.0 (46.0, 89.5)	82.7 (35.7,97.6)
5)	How much money was spent on self-medication?	Free	26.8 (12.1, 49.2)	73.0 (46.0, 89.5)	82.7 (35.7,97.6)
		≤RM30	62.3 (39.6, 80.6)	27.0 (10.5, 54.0)	-
		>RM30	11.0 (2.7, 35.1)	-	17.3 (2.4, 64.3)

Results presented as percentage (confidence interval)

7.7.3 Indirect needs in outpatient services

Despite not experiencing an acute event in the preceding two weeks, there was a subgroup of older people from the population who used the outpatient facilities (Table 7.5). Among the frail older people who did not experience any injury or illness, 61.5 percent (95% CI 36.8, 81.4) of them utilized outpatient services as compared to 30.3 percent (95% CI 25.4, 35.7) and 22.1 percent (95% CI 17.8, 27.2) in the pre-frail and robust groups respectively. There was a high need for outpatient services among the frail older people.

Among the frail the most cited reasons for outpatient utilization despite not having an acute need were for further diagnosis of an illness (34.2 percent, 95% CI 11.4, 67.7) and regular supply of vitamins and supplementation (31.3 percent, 95% CI 10.3, 64.3). However, the main reason cited by 64 percent of pre-frail and 44.1 percent of robust older people was for follow up for their pre-existing illnesses.

The frail group utilized government primary care facilities (34.5 percent, 95% CI 7.8, 57.6) and private GP or private hospital services (36.0 percent 95% CI 12.6, 69.2) equally. Government primary care seemed to be the favoured healthcare facility for 61.6 percent (95% CI 43.9, 63.4) pre-frail and 68.2 percent (95% CI 46.1, 78.6) robust older people respectively as compared to 34.5 percent (95% CI 7.8, 57.6) of frail older people. There was higher utilization of private general practitioner clinics or private hospitals among the frail (36.0 percent, 95% CI 12.6, 69.2) as compared to the pre-frail (13.8 percent, 95% CI 7.4, 20.9) and robust 17.5 percent, 95% CI 9.7, 26.6) older people. Among those categorized as frail, 20.2 percent (95% CI 1.5, 45.8) of them purchased medications over the counter at a pharmacy as compared to 2.9 percent (95% CI 0.9, 8.7) pre-frail older people and 1.3 percent (95% CI 0.2, 8.6) robust older people. Most of these frail older people who utilized healthcare without having the need for it usually visited a health facility only once. However, 18.4 percent of the frail older people needed up to three visits to a healthcare facility as compared to the pre-frail and robust older people who needed only one or at most two visits.

The expenses incurred by 98.0 percent of the older people in any of the three categories of older people (robust, pre-frail or frail) in this subgroup (those who utilize outpatient with no illness/injury) ranged from free of charge to a maximum of RM100.00. Approximately, 54.4 percent (95% CI, 43.1, 65.3) robust older people had an average expenditure of less than RM50.00 as compared to 36.7 percent (95% CI 27.7, 46.7) pre-frail and 18.4 percent (95% CI 4.5, 51.8) frail older people. However when the average

expenditure increased to more than RM50.00, the frail older people spent (47.1 percent, 95% CI 19.7, 76.4) spent more than the pre-frail (10.2 percent, 95% CI 5.4, 18.1) and robust (4.9 percent, 95% CI 1.8, 12.6) groups.

Table 7.5 Older people not ill or injured in last two weeks but utilized outpatient care services (Indirect needs)

No.	Item	Options	Robust	Prefrail	Frail
1)	Have you had injury or illness in the past 2 weeks	No	85.8 (81.8, 89.0)	83.9(79.7, 87.3)	65.0 (43.9, 81.5)
2)	Have you ever received outpatient care in the last 2 weeks?	Yes	22.1 (17.8, 27.2)	30.3 (25.4, 35.7)	61.5 (36.8, 81.4)
3)	Reason for using outpatient services	Medical check-up	4.3 (1.4, 12.9)	1.0 (0.1, 6.6)	-
		Follow up	44.1 (33.3, 55.6)	64.0 (54.2, 72.8)	16.6 (4.0, 48.8)
		Dental treatment	4.0 (1.3, 11.9)	0.8 (0.1, 5.3)	6.9 (0.9, 37.1)
		Vitamins and supplementation	27.6 (18.4, 39.2)	22.4 (15.2, 31.7)	31.3 (10.3, 64.3)
		Further diagnosis	13.6 (7.6, 23.1)	11.0 (6.3, 18.6)	34.2 (11.4, 67.7)
		Blood donation	1.4 (0.2, 9.3)	-	-
		Others	4.9 (1.8, 12.5)	0.8 (0.1, 5.3)	11.0 (1.5, 49.8)
4a)	Type of facility visited as 1st option	Public hospitals	13.1 (3.3, 16.0)	22.2 (6.9, 20.3)	9.2 (1.3, 44.8)
		PrivateGP/ hospitals	17.5 (9.7, 26.6)	13.8 (7.4, 20.9)	36.0 (12.3, 69.2)
		Primary care	68.2 (46.1, 78.6)	61.1 (43.9, 63.4)	34.5 (7.8, 57.6)
		Pharmacy (OTC)	1.3 (0.2, 8.6)	2.9 (0.9, 8.7)	20.2 (1.5, 49.8)
4b)	Type of facility used as 2nd option	Public hospitals	66.7(11.1, 97.0)	-	-
		PrivateGP/ hospitals	-	100.0 (100.0, 100.0)	100.0 (100.0, 100.0)
		Primary care	33.3 (13.2, 88.9)	-	-
		Pharmacy (OTC)	-	-	-
5a)	No. of visits to 1st health facility	1 visit	100.0 (100.0, 100.0)	98.2 (93.1, 99.6)	81.6 (48.2, 95.9)
		2 visit	-	1.8 (0.4, 6.9)	-
		3 visit	-	-	18.4 (1.3, 44.7)
5b)	No. of visits to 2nd health facility	1visit	100.0 (100.0, 100.0)	100.0(100.0, 100.0)	100.0 (100.0, 100.0)
6a)	Total expenditure for 1st visit	Free	38.2 (28.0, 49.5)	51.4 (41.6, 61.1)	34.5 (12.6, 65.8)
		≤RM50	54.4 (43.1, 65.3)	36.7 (27.7, 46.7)	18.4 (4.5, 51.8)
		RM51-RM100	4.9 (1.8, 12.6)	10.2 (5.5, 18.1)	47.1 (19.7, 76.4)
		RM101-RM200	2.5 (0.6, 9.4)	0.9 (0.1, 6.1)	-
		>RM200	-	0.4 (0.1, 3.1)	-
6b)	Total expenditure for 2nd visit	Free	33.3 (3.0, 88.9)	-	-
		≤RM50	66.7 (11.1, 97.0)	-	100.0 (100.0, 100.0)
		RM51-RM100	-	-	-
		RM101-RM200	-	-	-
		>RM200	-	100.0 (100.0, 100.0)	-

Results presented as percentage (confidence interval)

7.8 Results of inpatient utilization (hospitalization)

This study shows that 30.7 percent (95% CI 15.7, 51.2) older people who are frail have been hospitalized in the last one year which was higher than the older people in the pre-frail (12.2 percent, 95% CI 9.2, 16.0) or robust (5.5 percent, 95% CI 3.6, 8.4) groups (Table 7.6). The older people who were frail only chose public hospitals as their choice for hospitalization, however only 79 percent (95% CI 55.6, 90.5) of the robust and 82.8 percent (95% CI 73.7, 94.1) of the pre-frail chose the public hospitals as their first choice.

More than 90.0 percent of all three groups; robust, pre-frail or frail had an average of one admission in the preceding year. However, only the robust and pre-frail groups reported more than one admission. More than 70.0 percent of them in any one of the subgroups had shorter duration of stay (less than seven days) during the first admission however 24.5 percent of the frail older people stayed more than seven days during their first admission. If the admission was for the second time, 72.6 percent (95% CI 19.2, 96.7) pre-frail older people stayed more than seven days and only 46.5 percent (95% CI 10.9, 86.1) in the robust group stayed more than seven days.

The total expenditure for the duration of stay was mostly below RM500.00 or in most cases free of charge supporting the preference for public hospitals. Only 18.2 percent of robust and 16.3 percent of pre-frail older people who were admitted at private hospitals spent more than RM1000.00 for their hospital bills. None of them from the frail subgroup spent more than RM500.00. However, among the pre-frail older people 1.9 percent (95%CI 0.9, 12.6) of them had to spend more than RM5000 for their first admission.

Among the pre-frail older people, 6.6 percent (95% CI 7.1, 18.9) of them required second admission. Average expenditure during the second admission was higher among the pre-frail older people where 27.4 percent (95% CI 3.3, 80.8) spent more than

RM5000.00 as compared to the robust group whose highest value spent ranged between RM1001 to RM2500.00. Two respondents in this study explained that private healthcare bills can be as exorbitant RM10000 and more.

Table 7.6 Older people who utilized inpatient services (hospitalization) over the last year by frailty status

No.	Item	Options	Robust	Prefrail	Frail
1)	Have you been hospitalized in the last 1year?	Yes	5.5 (3.6, 8.4)	12.2 (9.2, 16.0)	30.7 (15.7, 51.2)
		No	94.5 (9.6,96.4)	87.8 (84.0, 90.8)	69.3 (48.8, 84.3)
2)	Average hospitalization in 1 year	1	92.0(72.6, 98.0)	93.4(81.8, 97.9)	100.0 (100.0, 100.0)
		2	4.2 (0.6, 24.6)	6.6 (7.1, 18.9)	-
		3	3.9 (0.5, 23.2)	-	-
3a)	1st choice of health facility for admission	Public	77.5 (55.6, 90.5)	87.0 (73.7, 94.1)	100.0 (100.0, 100.0)
		Private	22.5 (9.5, 44.4)	13.0 (5.9, 26.3)	-
3b)	2nd choice of health facility for admission	Public	46.5 (10.9, 86.1)	79.2 (28.2, 97.4)	-
		Private	53.5 (13.9, 89.1)	20.8 (2.6, 71.8)	-
3c)	3rd choice of health facility for admission	Public	46.4 (5.1, 93.3)	-	-
		Private	53.6 (6.7, 94.9)	-	-
4a)	Average duration of stay for 1st admission	≤7 days	79.0 (54.8, 92.1)	82.8 (69.1, 91.3)	75.5 (38.0, 93.9)
		>7 days	21.0 (7.9, 45.2)	17.2 (8.7, 30.9)	24.5 (6.1, 62.0)
4b)	Average duration of stay at 2nd admission	≤7 days	53.5 (13.9, 89.1)	27.4 (3.3, 80.8)	-
		>7 days	46.5 (10.9, 86.1)	72.6 (19.2, 96.7)	-
4c)	Average duration of stay at 3rd admission	≤7 days	53.6 (6.7, 94.9)	-	-
		>7 days	46.4 (5.1, 93.3)	-	-
5a)	Average expenditure for 1st visit	Free	39.0 (21.2,60.4)	22.0 (12.1, 36.5)	21.2 (5.1, 57.4)
		<RM500	42.7 (23.7, 64.2)	61.7 (46.8, 74.7)	78.8 (42.6, 94.9)
		RM501-RM1000	-	5.7 (1.8, 16.4)	-
		RM1001-RM2500	4.6 (0.6, 26.7)	6.6 (2.1, 18.9)	-
		RM2501-RM5000	13.6 (4.3, 35.2)	2.1 (0.3, 13.5)	-
		>5000	-	1.9 (0.3, 12.6)	-

Results presented as percentage (confidence interval)

7.9 Discussion

This chapter intended to understand the association between frailty status and healthcare utilization patterns. From this chapter, we do see an increase in healthcare utilization patterns (outpatient and inpatient) among the pre-frail and frail category as compared to those who are robust. The literature for specific patterns of healthcare utilization among frail older people is scarce (Hoeck et al., 2012). In an attempt to fill this gap healthcare utilization patterns have been studied among Belgian older people (Hoeck et al., 2012) and community dwelling older people in Europe (Ilinca & Calciolari, 2015) which found increased patterns of utilization among the frail older people. Another study involving 10 European countries (SHARE study) similarly found that frail older people had three times more primary and hospital care utilization as compared to robust individuals (Ilinca & Calciolari, 2015).

Among the older people who had a direct need for healthcare services, the utilization of healthcare services showed a decreasing trend as the level of frailty increased. The frail older people only opted for outpatient public health services such as primary care clinics as their choice of healthcare provider. However, as the level of frailty improved, respondents also show equal preference for private general practitioners clinic. The percentages of older people who spent more than RM100.00 during their first outpatient visit increased as the level of frailty increased.

A study done by Roberts, McKay, and Shaffer (2008) found that emergency department visits of patients aged 64 to 74 years increased by 34 percent over 10 years (1993 to 2003). Similarly, in a systematic review done by Samaras, Chevalley, Samaras, and Gold (2010) on emergency department visits by older people in four countries showed that older people account for 12 to 24 percent of all emergency department visits. These findings are similar to the increased patterns of acute illness seen among frail older people as shown in this study. The utilization patterns among the frail however showed

a decreasing trend contrary to what is seen in other countries. A study involving 6057 older people aged 65 and above was done in Northern California found that outpatient utilization patterns among older people increased by 17 percent and was mainly contributed by diagnosis related to cardiovascular diseases, musculoskeletal conditions and frailty (Haan et al., 1997). Frail Belgian older people had increased odds of contact with a general practitioner (GP) (OR 4.35) or a specialist (OR1.75) or emergency visits (OR 6.20) as compared to healthy community dwelling Belgian older people (Hoeck et al., 2012).

This finding is important because if the frail older people who are known to have complex health conditions are not receiving the due care they need it may further exacerbate their condition or lead to premature mortality.

Therefore, the next subgroup of older people identified are those who had unmet needs in the utilization of healthcare services. The proportion of older people with unmet needs increased as the level of frailty increased. Among the frail respondents who had the need to utilize the healthcare services but did not get the needed care cited either transport unavailability or illness not being severe as their main reasons. This suggests that as the frailty status increases the older people are highly dependent on the availability of transport when they need to access the healthcare facility. Most of these frail older people were likely dependent on their children or caregiver for transportation to access a health care facility. A study involving frail older people people in United States also found that availability of transportation was the main reason one could not access health services and this was further exacerbated by social isolation from family or neighbourhood (Barbara Rittner & Alan B. Kirk, 1995).

The pre-frail older people choose to visit a health facility only if the illness is perceived as severe. The Third National Health and Morbidity Survey done in 2011 in Malaysia found that 70.5 percent of the older people aged 65 to 69 and 75.3 percent among those

aged 70 to 74 perceived that their sickness was not severe enough to warrant treatment (Institute of Public Health, 2011).

Among these older people who do not access an outpatient service for an acute event, the attempts to self medicate decreases with increasing levels of frailty. There are several studies that show a high prevalence of self medication among community dwelling older people. However, data on self medication among frail older people is lacking (Jerez-Roig et al., 2014). The 2011 National Health and Morbidity Survey reported that 43.5 percent of older people in Malaysia attempted to self medicate following an illness but this dropped to 31.3 percent among the older people aged 75 and above (Institute of Public Health & Institute of Health Systems Research, 2012). This is probably because the likelihood of frailty and co-morbidities increase with age and decision to self-medicate becomes more difficult. Most of the frail older people did not spend money for their attempts to self medicate and the likely reason for this would be using home based remedies which did not need them to fork out money. However, as seen in this study if the average expenditure for self medication increased the frail older people needed to spend more than the robust group because of the complexity of their illness.

The third group of older people that was studied were the frail older people who accessed the healthcare services on a regular basis (indirect need). The indirect need for outpatient services increased as the level of frailty increased. The reason cited most commonly for an indirect need was for further diagnosis of an illness. The pre-frail older people cited their reason as the need for follow up in the clinics for a pre-existing condition indicating the large number burdened by chronic illness in the pre-frail categories. In the SHARE study, a pre-frail or frail individual had 1.2 and 1.5 times the odds of having a doctor's visit as compared to robust individuals. The presence of multi-morbidity in an older person also increased the odds of visits to a doctor by 1.4

times (Ilinca & Calciolari, 2015) From the findings of the SHARE study, we can expect that the older people in this study with pre-existing illnesses will have higher odds of utilization of outpatient services if the level of frailty continues to worsen. This in turn will cause a massive burden on the provision of healthcare services and cost in the future.

In comparison to the direct needs, there was a higher usage of private general practitioners or private hospitals among the frail for indirect needs. With the increased demand and urgency in health issues among the frail those who can afford out of pocket tend to access the private health facilities. This is probably due to the long waiting time seen in the public hospitals (Risso-Gill et al., 2015). The average expenditure per visit increased as the level of frailty increased. It has also been established in several studies that there is a disproportionate consumption of healthcare resources by frail older people (L. F. Liu, 2014; Olga Theou et al., 2013). In this study the higher expenditure seen with increasing levels of frailty could have also been contributed by the choice to go to a private GP or hospital, the decision to purchase medications or buy vitamins and supplements over the counter from a pharmacist but which require out of pocket expenditure.

There is higher inpatient utilization as the level of frailty increases. Increased hospitalization rate has been evidenced as a strong outcome of many longitudinal studies done on frail older people (Robinson et al., 2011; Rochat et al., 2010).

The pattern of hospitalization with frailty is similar to the findings among Belgian community dwelling older people. Frail Belgian older people had increased odds of hospitalization as compared to healthy Belgian older people (Hoeck et al., 2012). For inpatient utilization, the preference for the public healthcare system was evident in all categories; robust, pre-frail or frail. In Malaysia, medical fees at the private hospital can be exorbitant and is usually accessed by those who have a self-purchased private health

insurance, employer provided health coverage or have the capacity to pay out of pocket whereas the public hospitals are highly subsidized though general taxation and the cost of admission is still affordable (H. T. Chua & J. C. Cheah, 2012).

Longer duration of stay in hospitals and higher expenditure patterns were seen as the level of frailty increased. If a second admission was required 21.0 percent of the pre-frail older people did consider admission at a private hospital and this decision contributed to the higher expenditure seen among the pre-frail group during the second admission. The higher expenditure could have been also contributed by longer hospital stay in the second admission. Longer hospital stays contributing to high healthcare costs were also seen among the frail older people in India (Kehusmaa et al., 2012) and North America (Shubert, 2011). Even though the frail older people did not report any episode of readmissions, there was 2.3 percent more pre-frail older people in this study who needed readmission as compared to the robust older people. A study involving 6000 older people over nine years in Northern California found that the probability of readmission increased by 120.0 percent for conditions related to frailty (Haan et al., 1997).

The strength of this study is that is fills the gap of knowledge on health utilization patterns among the older people in Malaysia especially when they are frail. The information obtained here highlights the influence of frailty among the older people, their current needs and most importantly barriers they face in their decision to utilize health services. Trends in utilization seen here would assist in addressing the type of care needed, identifying areas in healthcare services that are lacking and projecting future health and resource needs. This study utilizes the similar health utilization framework used in the National Health and Morbidity Survey and can be used to compare data between the older people found in this study and nationwide.

However, there are several limitations in this study. First, this being a cross sectional study prevents a causal relationship to be established between frailty and healthcare utilization. The cost data could only be obtained from patient or caregivers information and in some instances from records of receipt for payment. For future studies on economic evaluation of healthcare utilization, it is better to obtain data from hospital records to avoid bias. It is imperative to further strengthen the findings in this study, and a strong database should be in place to monitor the healthcare utilization data of older people in Malaysia.

In this chapter we found that there is a higher healthcare utilization and healthcare expenditure as the level of frailty increases. Apart from the ability to afford good healthcare, they have difficulties in accessing these health centres due to the lack of transport. To enable them to overcome these shortcomings a robust family support has to be in place. The role that the family plays and the capacity to maintain a healthy relationship with their parents or older people is based on the ability to cope with the burden of care that these family caregivers are faced with.

This perspective of caregiver burden and how the condition of frailty influences this burden is explored in the next chapter.

CHAPTER 8 CAREGIVER BURDEN AND ITS ASSOCIATION TO FRAILTY

8.1 Introduction

In the earlier years, the word care-giving was almost always associated with infants and children but in the last decade with the demographics shifting in many countries the concept of care-giving for older people has become a prominent topic. This phenomenon is fervently researched these days as the gerontological speciality has evolved tremendously from the curative perspective to a healthy ageing perspective. The fervour with which this issue is being addressed is mainly caused by the increasing proportion of women who are childless, changes in marriage and divorce patterns contributing to the shrinking pool of family support (Wolf, 2001). The demographic trends in Malaysia also show similar changes with declining fertility rates, feminization of workforce and high levels of migration (Mahari, 2011). This will result in declining numbers of potential caregivers for the older people in Malaysia forcing our older people to fend for themselves as they age.

We do not have much data on the burden of care-giving for frail older people in Malaysia. This chapter looks into the prevalence of caregiver burden among caregivers of frail older people and to ascertain the association between frailty and caregiver burden. The concept of burden in this study is operationalized through care provided by informal caregivers (unpaid care). Although it is a known fact that complementing the care-giving process with the help of a maid (formal paid care) is a common practice among Malaysians, the formal and informal care are very task specific and subject to different types of care-giving experiences. The ability to enlist these formal services is also dependent on the informal caregiver's need and ability to pay.

Section 8.2 starts with the description of the definition of the caregiver followed by discussion on various types of burden experienced by caregivers in Section 8.3. Section 8.4 describes the prevalence of caregiver burden among the frail older people and the following section (Section 8.5) discusses factors that contribute to the burden of care giving in older people. The various ways to measure the concept of care giving burden is described in Section 8.6 and the conceptual framework used to describe the objective of this chapter are given in Section 8.7. Section 8.8 describes the methodology used for this objective and the results are depicted in Section 8.9. Section 8.10 summarizes the findings of this chapter.

8.2 Definition of a caregiver

The complexities of defining a caregiver begins when the true meaning is explored through the lens as described by the caregiver themselves. Identifying the informal care giving burden among the older people in a population is crucial as the caregiver's role not only influences the health and quality of life of the older person but also has bearing on the impact the formal care-giving process has on the recipient.

Defining a care-giver is the first and foremost step required to identify as to who plays the role of care-giving and the responsibilities associated with that designated role. A caregiver/carer has been described by the Oxford Dictionary as a 'family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person' . Similarly, according to the Merriam-Webster's Online Dictionary, the medical definition of "caregiver" is a person who provides direct care (as for children, elderly people, or the chronically ill). A caregiver is usually a family member, or friend who willingly sacrifices time, energy and, in some cases, their entire being to tend to the needs of a loved one. The true meaning of "caregiver" is not represented by "one person does it all." Being a great caregiver can be a team effort (Hunt & Watson, 2010). While the provision of basic physical, emotional and psychological needs are fulfilled by the family caregiver, government health and social programs, national and local advocacy groups and respite care that is available is needed to support this care giving system. Technological advances have made it possible to access a wealth of information and resources to enable the caregivers to provide better and informed care for their older people (Hunt & Watson, 2010)

The types of caregivers have been generally divided into two groups: those providing formal and informal care (A. P. Williams et al., 2010).

a) Formal care – paid care provided by professionals, usually the health and social system in the country, or by provision of a paid caregiver.
b) Informal care – unpaid care provided by family, friends and volunteer

The definition of informal care-giving process (unpaid care) is rather challenging as some carers do not perceive it as a role but rather a responsibility. There are two hypotheses currently on the relationship between formal and informal care. Some authors believe that formal care eventually substitutes informal care (Agree, Freedman, Cornman, Wolf, & Marcotte, 2005), however, there is evidence that the two types of caregiving processes are complementary indicating collaboration between the two systems (Sundström, Malmberg, & Johansson, 2006). There should be a balance in the two types of care providing mechanisms to ensure the quality of life of the older people. Though the presence of formal care givers is to complement the informal caregiving process, interestingly a study in Malaysia found that informal caregivers receiving assistance from maids or private nurses did not have any alleviation of their burden from this assistance (Zheng-Yi, Ming-Ming, Siok-Hwa, & Ahmad, 2013).

8.3 Types of burden

Braithwaite (1992) critically examined the concept of burden and found that its lack of clear definition and the inconsistency between its conceptualization and operationalization has to be addressed to translate the research into a scientifically useful and relevant policy. The overall impact of physical, psychological, social and financial demands of care-giving has been defined as caregiver burden (L. K. George & Gwyther, 1986). A family caregiver is defined as one who provides assistance to a person with a chronic and disabling condition. The burden experienced is not limited to physical and psychological sufferings in a caregiver due to the recipient's condition but significant burden arising from the financial perspective of care giving (Collins &

Swartz, 2011). Gratao et al. (2012) describe that as a result of providing dignified care to an older adult with some form of disability or health issue most carers experience some form of positive or negative feelings, psychological conflicts, distress, insecurity or fear especially with progression of the primary disease". Hence, for a caregiver to assume the task of care giving without the appropriate training, knowledge or support to play that role requires painstaking effort which results in the burden felt.

Montgomery, Gonyea, and Hooyman (1985) differentiated this burden into two relevant aspects of informal care which are objective and subjective burden. Objective burden refers to the care tasks performed by the caregiver, financial constraints and time investment whereas subjective burden indicates the extent to which emotional, relationship and personal strain takes a toll on the caregiver (Brouwer et al., 2004). A study done by Wolfs et al. (2012) found high levels of objective and subjective burden experienced by caregivers of patients with dementia in China, a country without formal caregiver support. Similarly, a community based study involving 15 communities from three Eastern cities of China; found that subjective caregiver burden was the strongest predictor of both mental and physical quality of life in the caregiver (Yang, Hao, George, & Wang, 2012).

The multidimensionality of burden has been investigated by several authors who found new domains that explain burden experienced by the caregiver adequately (Ankri et al., 2005; Savundaranayagam et al., 2010). Given that the care-giving process sits on the pre-existing interpersonal relationship, care-giving responsibilities may negatively affect that relationship which gives rise to a burden called relationship burden. Interference in the personal life and invasion of personal privacy of the care-giver were labelled as objective burden. These two domains coupled with the third form of burden

which is the stress burden which arises out of emotional anxiety or stress from the care giving process, completes the multidimensionality (Savundaranayagam et al., 2010).

8.4 Caregiver burden among the frail

The concept of burden is usually seen in the informal care as it is much more confined to the relationship between the carer and the recipient and the emotional ties they are bonded by. The care giver may be a family member, life partner, friend or in some instances all three of them and the burden usually encompasses physical, psychological emotional and financial aspects of care-giving (Lai, 2012; Zarit et al., 1980; Zarit, Todd, & Zarit, 1986).

The burden faced by these caregivers can be in terms of mental stress or physical constraints. A study done by Garlo, O'Leary, Van Ness, and Fried (2010) on caregivers of 179 community dwelling older people, the older people with chronic illnesses showed that high burden was associated with caregivers needing more help with daily tasks. Since the majority of older people especially those ridden with dementia stay at home and are cared for by their spouse or older child, physical or mental health issues have been identified among the caregivers (Flick, 2004).

Caregiver burden in general population has been studied before. However, caregiving research on specific groups are still lacking (V. K. Pillay & Levy, 2012). In gerontological research we have seen burden measured among caregivers of Alzheimer's (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991), Parkinson's (Goldsworthy & Knowles, 2008) and dementia patients, and caregivers of depressive (Scazufca, Menezes, & Almeida, 2002) and physically disabled older people (Salama & Abou El-Soud, 2012). Frail older people suffer from a myriad of age-related problems and are at risk for falls, disability and death and as a result of the continuously changing

problems among them. Thus, providing care entails intensive tasks over prolonged periods of time (Janse, Huijsman, Maurice de Kuyper, & Fabbricotti, 2014). Not all aspects of care giving experience are negative but there are positive experiences described in some papers such as increased gratification, improved familial relationships and feelings of usefulness (Beach, Schulz, Yee, & Jackson, 2000).

There is a dearth of data on the burden experienced by caregivers of frail older people. A study done in Sao Paulo, Brazil did try to fill this gap and the authors found that eight percent of the caregivers of frail older people experienced moderate to high burden (Stackfleth et al., 2012). This paper also highlighted a finding that in Portugal the percentage of burden was up to 41 percent. However, this was among the older people who needed assistance to perform their activities of daily living.

8.5 Factors associated with caregiver burden

Various factors that contribute to the burden of a caregiver have been studied over three decades and the magnitude of the issue has been highlighted in various older populations (Horwitz & Reinhard, 1995; Lai, 2012; Scazufca et al., 2002; Zarit et al., 1980).

Socio-demographic characteristics of the caregiver such as age, gender, marital status, ethnicity, education and income level have been studied in the past and found to affect the care-giving process. The age of care-givers showed an inverse relationship with burden in Italy indicating younger caregivers experience higher burden (Rinaldi et al., 2005). This finding was echoed in a study in the United States where those aged less than 55 years experienced higher burden than their older counterparts (Cain & Wicks, 2000). Women have been found to experience higher levels of burden than their male equivalent repeatedly (Buchanan, Radin, & Huang, 2011; Martin Pinquart & Sörensen,

2003). This was likely to be due to the multiple roles assumed by women to manage her daily life. One study found that when caring for care-recipients with anger issues the coping mechanisms were difficult for women as compared to men who provided care (Bedard et al., 2005). The burden experienced by adult child caregivers was much greater than spouses living with older people in Spain and this burden was mainly caused by the guilt to provide for their older people and managing their own family duties (Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, & Lopez-Pousa, 2010). Attention to cross-cultural differences among caregivers have been looked into in the past and ethnic differences in burden experience have been seen (Knight et al., 2002). Asian subgroups were the most studied due to their strong sense of filial responsibility and its varied effect on care-giving hence making it a strong contributor to burden (Miyawaki, 2015). The other profiles investigated in relation to care-giving burden were education level and income linking the economic and financial burden experienced in the act of care-giving (Lai, 2012; J. Li, Lambert, & Lambert, 2007). Lower education levels and lower incomes causing more burdens was the general pattern seen. Past work by Ludecke, Mnich, and Kofahl (2012) has also shown that demographic characteristics of the caregivers can play a major role influencing the perception of burden.

A study done in Malaysia by Zainuddin et al. (2003) showed that shorter duration of care-giving which was two years or less was associated with higher burden of care-giving. These findings were also observed in a group of caregivers providing for older people with dementia (Nurfatihah et al., 2013). In Japan, Matsuu, Washio, Arai, and Ide (2000) highlighted that duration of care-giving was associated with depression among the long duration caregivers which led to a vicious downhill cycle of burden.

A study done by Thommessen et al. (2002) highlights the importance of cognitive status when caring for older people especially when ridden with severe co-morbidity. A higher

degree of mental or physical disablement in the care recipient directly increases the higher degree of burden felt by the caregivers due to higher levels of dependency (M. Lee, Yoon, & Kropf, 2007; Zarit et al., 1980). Cognitive impairment was identified as a confounder in care giving burden in several studies (Bajaj & Sinha, 2009; Bruce, McQuiggan, Williams, Westervelt, & Tremont, 2008).

Disease progression and disability in the care-recipient are known determinants of caregiver burden (Marvardi et al., 2005). A study assessing the multidimensional predictors affecting caregivers of patients with dementia found that disease related factors explained 16 percent of the care-giving burden (Kim, Chang, Rose, & Kim, 2012).

Unlike professional caregivers such as physicians and nurses, informal caregivers, typically family members or friends, provide care to close and loved ones. The difficulty they face is not limited to just the disease burden such as cancer, chronic illness, depression or dementia which is common in older people but to deal with the unrelenting stress caused by their own financial or time constraints (Garlo et al., 2010; Hsu et al., 2014). Frailty which is a common consequence of ageing presents many more challenges with combination of co-morbidities and disabilities increasing the complexity of the condition. Frailty has been shown to increase the likelihood of institutionalization (Matsuzawa, Sakurai, Kuranaga, Endo, & Yokono, 2011), neglect (Pruszynski, Gebska-Kuczerowska, Cicha-Mikolajczyk, & Gromulska, 2011) and abuse (R. T. Brown, Kiely, Bharel, & Mitchell, 2013) pointing towards poor social support system. Interventions to reduce or alleviate the burden experienced by care-givers for the older people have been shown to reduce outcomes like institutionalization, neglect and abuse (Hiel et al., 2015; Kuwahara, Washio, & Arai, 2001; Richard Schulz, Martire, & Klinger, 2005).

8.6 Measuring caregiver burden

The ageing process comes with its fair share of demands; in general the needs of these frail older people may range from physical assistance, psychological support, and financial support. The process of care giving comes with its equal share of negative consequences to both the carer and the recipient. One of the most frequently studied consequences is the burden experienced by the carers of these older people as increasing levels of burden among carers have been known to contribute to poor family dynamics (Abdollahpour, Noroozian, Nedjat, & Majdzadeh, 2012)

Caregiver burden has been operationalized in several ways in the last decade (Bobinac, Van Exel, Rutten, & Brouwer, 2010; Braithwaite, 1992; Glanville & Dixon, 2005). Powell and Teresi (1994) authors of the Annual Review of Gerontology and Geriatrics, discussed that most studies depict caregiver burden as a complex multidimensional condition. Some studies adopt a dichotomous concept such as subjective and objective burden and some studies have added strain and stress to their domains. Some study models have also included costing into their context definition (Lai, 2012) such as direct monetary cost related to care-giving expenses and indirect costs in employment related due to one having to perform the caregiver role.

Various tools have been used to measure the burden of care among the older people population over the last few decades (Al-Janabi et al., 2010; Braithwaite, 1992; Brouwer et al., 2006). Due to the plethora of caregiver burden screening tools there is a lack in standardization of the domains and consensus as to which would be the best tool to use (Whalen & Buchholz, 2009). The systematic review by Whalen and Buchholz (2009) found that out of 74 caregiver burden screening tools that were identified, the Zarit Burden Interview, Caregiver Reaction Assessment and Caregiver Burden Inventory were the most frequently examined and reported tools.

It is imperative that we understand the burden of care among carers of frail older people in Malaysia as most of the carers would be pressured by the obligation to provide for their older people as they age. Most informal care providers in Asian countries do not shirk their duty or obligation to their older people and are bound by an age old Confucian philosophy known as 'filial piety' that the Asian culture is steeped in (Chow, 2006). Chow further describes how this traditional value can be construed by the younger generation in many levels and the sense of obligation they have. The newer sense of caring has evolved to a 'subcontracted' form where adult children still provide care through non family caregivers, most commonly domestic helpers, and paying for these services through their private funds (Arifin E.N. & Ananta A., 2009). Another issue that can contribute to the pressure to provide for their older people is that in Malaysia we lack the common safety nets such as long term care insurance, social security schemes and private pension schemes for the retirees and aged senior citizens and the burden to provide for these senior citizens then fall back on the informal care providers (Zheng-Yi et al., 2013). The conceptual framework in Figure 8.1 describes the association between frailty and caregiver burden and the other factors that would influence this relationship.

8.7 Conceptual Framework

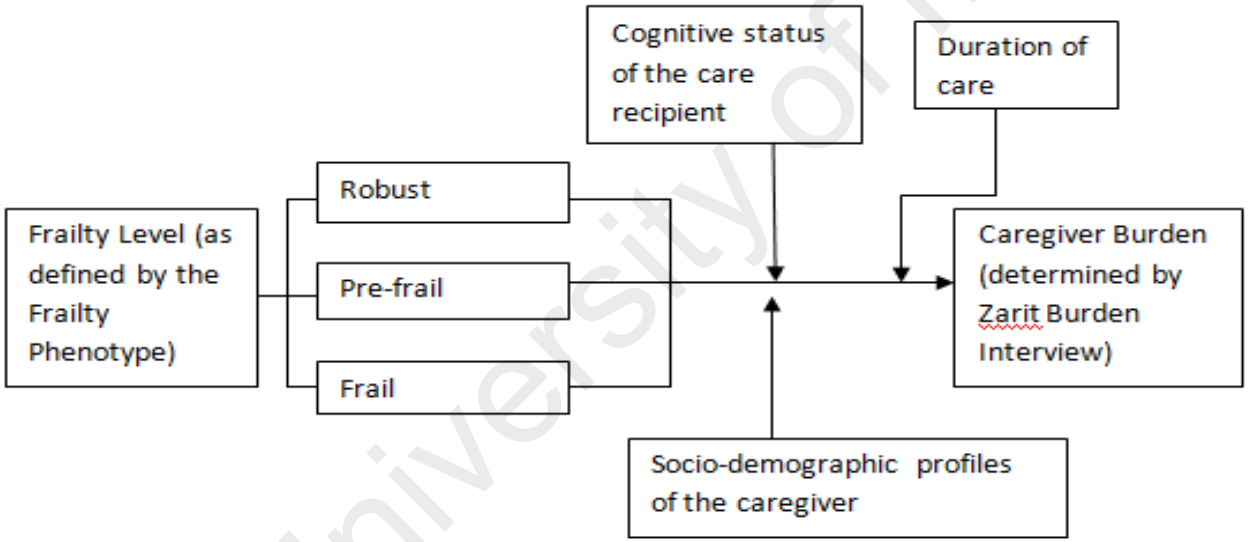

Figure 8.1 Conceptual framework of the association between frailty and caregiver burden

8.8 Materials and Methods

8.8.1 Study variables

The objective in this chapter was to understand how frailty influenced caregiver burden. Various confounders have been known to influence the outcome of caregiver burden among the older people. Literature has shown that being female, being older, those who were single, having low levels of income or education were significantly associated with higher levels of burden (Carretero, Garces, Rodenas, & Sanjose, 2009; Kim et al., 2012; R. Schulz & Martire, 2004). The variables used as confounder in this study were age, gender, marital status, ethnicity, education level and average monthly income.

8.8.2 Study Instruments

a) Socio-demographic variables of the caregiver that were collected are information regarding their age, gender, marital status, ethnicity, education level, average monthly income and relationship with the older people.

b) The burden of care giving was assessed using the Zarit Burden Inventory (ZBI) which was a 22-item questionnaire which measured the objective and subjective burden of caregivers. Each item is scored on a 5-point Likert scale ranging from 0 (never) to 4 (nearly always) with a total score range of 0-88. The 22- items in the tool measured three domains such as objective burden, relationship burden and stress burden and one global burden question. The sum of the score was then divided into four levels of burden where higher scores indicated greater burden (Schreiner et al., 2006). The ZBI measures in terms of the degree the caregiver experiences physical, psychological, emotional, social and financial issues resulting from the care-giving process. To date, there has been no normative cut-off values described in literature except higher scores indicating higher burden

levels. The recommended cut offs described by Hébert et al. (2000) were 0-22 (no to mild burden), 23-44 (mild to moderate burden), 45-66 (moderate to severe burden) and 67-88 (severe burden). Findings from a study by Schreiner et al. (2006) suggests that a cut-off score of 24 has significant predictive validity for identifying caregivers at risk of depression. It has been shown to have good reliability and validity (Seng et al., 2010) among Asians however the study population was for carers of patients with dementia. The ZBI was validated in this population as described earlier in Chapter 5.

c) Frailty was assessed using the Frailty Phenotype classification (described in Chapter 4, Section 4.6) because this tool has better predictive validity to examine short term adverse outcomes of frailty as described in Chapter 5, Section 5.9.

d) Cognition was determined using the Mini Mental State Examination (MMSE) and stratified by education status (described in Chapter 4, Section 4.6).

In accordance with the survey methodology described in Chapter 4, if the primary informal caregiver was present at the time of the survey, he or she was asked to fill the ZBI questionnaire. Out of the 789 older people who participated in the study for frailty assessment only 279 (35.4 percent) of them had a caregiver present at home at the time of the survey. Most of the older people were left alone at home when the family members had gone to work or the caregiver lived in a different household (n = 323). Some were left with their grandchildren (n =. 138). The remaining older people lived alone at home (n = 49). Each questionnaire was then checked for missing data and the score for each item was totalled to represent the final score for the ZBI. Higher scores indicated higher levels of distress; scores 0-20 (no to mild burden), 21-40 (mild to moderate burden) and ≥40 (moderate to severe burden) as interpreted in the study done by Hébert et al. (2000) which used the full 22-item ZBI tool.

8.8.3 Data management and analysis

All the data was entered into IBM Statistical Packages for Social Sciences (SPSS) Software Version 21.0 and coded for analysis. The total burden score for each individual was calculated and recoded into four different categories as described above. In this population, there was only one respondent among the pre-frail carers who had experienced severe burden so this category was combined with the category of moderate to severe burden for analysis.

Socio-demographic profiles of the caregiver were described using frequency and percentages. Since the response rate was only 35.4 percent, the results of the sample of 279 caregivers cannot be generalized to the caregiver population in Johor Bahru. The results presented in this chapter represent the findings for this sample of caregivers of the frail older people.

The prevalence of burden for the three groups of caregiver (caring for robust, pre-frail and frail) for the caregiver respondents in this study was determined and presented using frequency and percentages. To further investigate the contribution of frailty to the burden of care giving in this sample, multinomial logistic regression analysis was done. The regression analysis consisted of three consecutive models; the baseline results of caregiver burden with frailty as an independent variable (Model 1). In Model 2, the analysis was controlled for socio-demographic variables of the caregiver such as their age, gender, ethnicity, marital status, education level, average monthly income and duration of care. Finally in Model 3, the cognitive status of the older people was included. The odds ratio (confidence interval: CI) for each model is reported in the results.

8.8.4 Operational definition of terms

Table 8.1 Operational definitions of terms

Terminology	Operational Definition
Caregiver	Caregiver was defined as someone who provides physical, emotional and financial support for an older person in a non-professional and unpaid manner. All domestic helpers were excluded from this group as they were paid help. The caregiver in a family can provide three forms of support, physical, emotional and financial. In this case the one who the older person dependent on for most of their needs was taken as the caregiver.
Caregiver burden	The burden was perceived from three dimensions; objective burden (infringements in freedom and time resulting from care giving), stress burden (resulting in anxiety and tension) and relationship burden (resulting in changes in quality of the relationship between the giver and recipient) (Savundaranayagam et al., 2010).
Frailty Classification	The frailty level which is the independent variable being associated with the care-giver burden in this study will be measured using the phenotypic definition of frailty (as determined earlier in Chapter 5). Those with no positive finding from five predetermined parameters were considered robust, 1-2 positive findings were categorized as pre-frail and 3-5 positive findings classified as frail.

Table 8.1 Operational definitions of terms (continued)

Terminology	Operational Definition
Duration of care	A single question posed to determine the duration of the care giving process and divided into 3 groups. Long duration was more than five years, average duration as more than but less than five years and less than two years were considered as short duration. The duration of care was determined using the time cut-offs proposed by Zainuddin et al. (2003) which studied the burden of care among the older people influenced by duration of care in Malaysia.

8.9 Results

Table 8.2 describes the socio-demographic profiles of the caregivers of our study respondents. More than half of the caregivers were between the ages of 20 to 59 years of age (56.9 percent), followed by those above the age of 60 (40.0 percent). The caregivers between the ages of 20 to 59 were the children of the older people who participated in the survey and the caregivers aged 60 and above were the spouses of the interviewed. Three percent of the caregivers interviewed were the grandchildren or teenage relatives of the older participant. The majority of the caregivers were Malays matching the majority Malay older respondents, followed by Chinese and Indians. 67.4 percent of the primary caregivers were males. 7.5 percent of the caregivers were friends of the older people in the survey. 86.0 percent of the caregivers were married followed by single caregivers. More than half of the caregivers in this study had a secondary school education or higher (54.5 percent), followed by 35.5 percent of them having a primary school education at least. 66.0 percent of them lived in their own property and 28.6 percent of them lived in the ancestral property owned by their parents. Half of the caregivers reported an average monthly income below RM800.00. 41.2 percent of the caregivers depended on their child for their source of income, 16.8 percent depended on a government salary and 40.9 percent had a private income source. 37.0 percent of the caregivers had been involved in long term care followed by 29.0 percent with medium term care (between two to five years) and 23.3 percent short duration of care.

Most of the caregivers who cared for the frail older people were between 40 -59 years of age (75 percent) and 63.6 percent of them were the children of the frail older people as compared to only 39.5 percent and 46.5 percent of the children of the pre-frail and robust older people. 80.0 percent of the caregivers caring for the frail older people were involved in short duration of care as compared to the caregivers of the pre-frail and robust older people who had experienced longer duration of care.

Table 8.2 Socio-demographic profiles of caregivers by frailty status

Characteristics		Robust	Prefrail	Frail
Age	<19	5(3.5)	2(1.6)	1(8.3)
	20-39	32(22.2)	25(21.0)	1(8.3)
	40-59	47(32.6)	45(36.3)	9(75.0)
	>60	60(41.7)	51(41.1.)	1(8.3)
Ethnicity	Malay	136(94.4)	105(85.5)	10(83.3)
	Chinese	5(3.5)	11(8.9)	1(8.3)
	Indian	3(2.1)	7(5.6)	1(8.3)
Gender	Male	95(66.0)	84(67.7)	9(75.0)
	Female	49(34.0)	40(32.3)	3(25.0)
Relationship with respondent	Spouse	66(45.8)	60(48.4)	2(18.2)
	Child	67(46.5)	49(39.5)	7(63.6)
	Relative	4(2.8)	3(2.4)	0
	Friends	7(4.9)	12(9.7)	2(18.2)
Marital Status	Single	16(11.1)	14(11.3)	2(16.7)
	Married	125(86.8)	104(83.9)	10(83.3)
	Divorced	1(0.7)	2(1.6)	0
	Widow/Widower	2(1.4)	2(1.6)	0
	Cohabiting	0	2(1.6)	0
Education level	No schooling/formal school	18(12.5)	11(8.8)	0
	Primary school	46(31.9)	49(39.5)	4(33.3)
	Secondary school	66(47.2)	56(45.2)	8(66.7)
	Form6/Diploma/Certificate	11(7.6)	7(5.6)	0
	Degree (Bachelors/Masters/PhD)	3(2.1)	1(0.8)	0

Results presented as frequency (percentage)

Table 8.2 Socio-demographic profiles of caregivers by frailty status (continued)

Characteristics		Robust	Prefrail	Frail
Home ownership	Rental	4(2.8)	11(8.9)	1(8.3)
	Own property	96(66.7)	78(63.7)	9(75.0)
	Living with family/relatives/friends	44(30.6)	34(27.4)	2(16.7)
Average monthly income	RM0-RM260	40(27.8)	44(35.6)	10(80.0)
	RM261-RM800	47(32.4)	43(34.7)	2(20.0)
	RM801-RM2500	57(39.8)	36(29.7)	0
Source of income	Govt salary/Financial aid	30(20.8)	16(12.9)	1(8.3)
	Own income/ Private sector	55(38.2)	54(43.5)	5(41.7)
	From child	58(40.3)	52(41.9)	5(41.7)
	Public aid/NGO	0	1(0.8)	0
	No income	1(0.7)	1(0.8)	1(8.3)
Duration of care	Less than 2 years	25(17.4)	44(35.6)	10(80.0)
	2 years to 5 years	46(31.9)	43(34.7)	2(20.0)
	More than 5 years	73(50.7)	36(29.7)	0

Results presented as frequency (percentage)

The prevalence of caregivers experiencing different levels of burden caring for robust, pre-frail and frail older people is shown in Table 8.3. The results in this study show that the most of the caregivers experience none to mild burden of care-giving. However, some of them do experience mild to moderate levels of burden (pre-frail 22.0 percent and frail 50.0 percent). The prevalence of caregivers experiencing moderate to severe burden is 2.4 percent for pre-frail and 8.3 percent for the frail subgroups respectively.

Table 8.3 Caregiver burden by frailty status

Levels of burden	Levels of frailty		
	Robust	Pre-frail	Frail
No to mild burden	123 (85.4)	93 (75.6)	5 (41.6)
Mild to moderate	19 (13.2)	27 (22.0)	6 (50.0)
Moderate to severe	2 (1.4)	3 (2.4)	1 (8.3)

Results in frequency (percentage)

Table 8.4 shows the results of the three categories of frailty when burden is further categorized by their domains. 45.5 percent and 49.2 percent of carers of frail and pre-frail older people experienced objective burden predominantly. 62.8 percent of those

caring for the robust older people also experienced objective burden. The rest of the carers of the frail group were equally distributed into categories that experienced relationship burden and stress burden. There were several caregivers who experienced no burden at all (total scores of zero) however none were from those caring for the frail older people.

Table 8.4 Types of burden experienced by frailty status

Type of burden	Robust		Pre-frail		Frail	
	%	95%CI	%	95%CI	%	95%CI
No Burden	2.8	(1.0, 7.1)	4.8	(2.2, 10.4)	0	
RB	8.3	(4.8, 14.0)	11.3	(6.8, 18.2)	18.2	(4.6, 50.8)
OB	62.8	(54.6, 70.3)	49.2	(40.5, 57.9)	45.5	(20.2, 73.2)
SB	17.9	(12.5, 25.1)	25.0	(18.2, 33.1)	18.2	(4.6, 50.8)
RB and SB	2.1	(0.7, 6.2)	1.6	(0.4, 6.2)	18.2	(4.6, 50.8)
RB and OB	4.8	(2.3, 9.8)	4.0	(1.7, 9.3)	0	
SB and OB	1.4	(0.3, 5.4)	4.0	(1.7, 9.3)	0	

Results in percentage (confidence interval: CI), RB=relationship burden, OB=objective burden, SB=stress burden

Table 8.5 (Model 1) shows that frailty status of an older person is significantly associated with mild to moderate burden of care giving. Frailty status did not show any association to moderate to severe levels of caregiving burden. The burden experienced when caring for a pre-frail and frail individual was almost two times and seven times more respectively than when caring for robust healthy older people. The variance explained by frailty in caregiver burden was only six percent (R^2 = 0.06) indicating there were many other factors influencing burden in caring for the older people. To further explain the model, the socio-demographic profiles of the caregiver such as the age, gender, ethnicity, and marital status, relationship with the older people, education level and average monthly income which were known confounders were added into Model 2 (Table 8.6). Only the caregivers experiencing mild to moderate levels of burden had significant findings. Caring for the frail group had 5.6 times the odds of

experiencing mild to moderate burden than caring for healthy older people. The variance explained by this model was 19 percent (R^2 =0.19). In the third model (Model 3), the addition of cognitive status of the older respondent being cared for and socio-demographic profiles of the caregiver was done. The predictors in this model explained 25 percent (R^2 = 0.25) of the association between frailty and caregiver burden. Even in this model, only those experiencing mild to moderate burden while caring for frail older people showed significant associations. The caregivers of frail older people had 4.5 times the odds of experiencing mild to moderate levels of burden than the caregivers of robust older people (Table 8.7, Model 3).

Table 8.5 Multinomial regression of frailty and caregiver burden (unadjusted)

Model 1			95% Confidence Interval		
	B	Exp (B)	LB	UB	Sig
Moderate to severe burden					
Frail	2.52	12.40	.96	160.65	0.049
Prefrail	.69	2.00	.33	12.21	0.054
Robust	0	1			
Mild to moderate burden					
Frail	1.88	6.53	1.73	24.68	0.006
Pre-frail	.64	1.89	.99	3.61	0.053
Robust	0	1			

LB= lower bound, UB=upper bound, Significance set at p value <0.05; R^2 = 0.06

Table 8.6 Multinomial regression of frailty status and caregiver burden (controlled for sociodemographic profiles of the caregiver)

Model 2			95% Confidence Interval		
	B	Exp (B)	LB	UB	Sig
Mild to moderate burden					
Frail	1.72	5.57	1.36	22.89	0.017
Pre-frail	.65	2.00	.10	4.03	0.051
Robust	0	1			

LB= lower bound, UB=upper bound, Significance set at p value <0.05
Model 2: controlled for care-givers age, gender, marital status, ethnicity, relationship with respondent, education level, average monthly income and duration of care

Table 8.7 Ordinal regression of frailty status and caregiver burden (socio-demographic profiles of the caregiver and cognitively impaired respondents)

Model 3			95% Confidence Interval		
	B	Exp (B)	LB	UB	Sig
Mild to moderate burden					
Frail	1.51	4.54	1.07	19.23	0.040
Pre-frail	.62	1.86	.91	3.78	0.087
Robust	0	1			

LB= lower bound, UB=upper bound, Significance set at p value <0.05
Model 3: controlled for cognitive status of the respondent, care-givers age, gender, marital status, ethnicity, relationship with respondent, education level, average monthly income and duration of care

8.10 Discussion

In this study most of the caregivers did not experience high burden levels. However, the frail group had the highest percentage of caregivers with mild to moderate levels of burden as compared to the pre-frail and robust groups. This indicates that there is an increase in the burden experienced as the level of frailty increases. The burden levels reported here are similar to a study done in Brazil where eight percent of the carers of frail older people demonstrated moderate to high levels of burden (Stackfleth et al., 2012).

The mean age of the caregivers was 52.4 (standard deviation: SD 16.9) years. The majority of the caregivers were the child or spouse supporting a concept long discussed in a paper by Stone, Cafferata, and Sangl (1987) called the 'principle of substitution' where care-giving is hierarchical starting from the spouse as the first choice, followed by child and lastly family/relative. Three percent of carers of the older people in this study were less than 19 years old (ranged between ages 16 and 17). The children of these older people were the primary caregivers for these older people but due to time and financial constraints, the grandchildren were required to assist in these older people with their activities of daily living.

Most of the caregivers were male which seem contradictory to other studies (Garlo et al., 2010; Kuwahara et al., 2001). The male caregivers were mostly represented by the spouses of the older people care-recipients. This study included a financial role apart from emotional and psychological support to describe the context of a caregiver which would have contributed to higher numbers of male caregivers. Some of the older people perceived the role of care-giving primarily contributed from the financial protection they obtained from their children as they were not dependent for activities of daily

living. It would be relatively easy to provide financial support but not the time and love needed by the older people.

The caregivers that were available in the households visited were mostly Malays. This could have been due to the proportions of Malays which are significantly larger in the community but nevertheless one should also consider the probability of differences in employment by ethnicity in Malaysia. A study by Lim (2002) found that the Chinese and Indian women in Malaysia tend to be most likely employed despite unequal employment opportunities. Most of the studies done show that majority of the caregivers were married which was a consistent finding here.

The mean average monthly income of the caregivers was RM1430.79 (SD 1543.27) with a range between no sources of income to RM9000.00/month. The mean monthly salary in Malaysia reported in the Salaries and Wages Report 2014 was RM2231.00 (Department of Statistics Malaysia, 2015). The monthly incomes of the caregivers in this study sit far below the reported levels. This is very disturbing as it may impact the capacity of the caregiver to provide for the extended family with their looming financial burden. The sacrifices of this so-called "sandwich generation" has been highlighted in various studies (Parker & Patten, 2013; C. Williams, 2004).

A pertinent issue at hand here which requires further understanding is the authority one has in the care-giving process where a person who has no income, is burdened with the responsibility of care-giving usually the daughter or daughter-in law who is a homemaker. The problem arises when decisions have to be made. The authority then belongs to the co-caregiver who only provides financially but does not directly provide the emotional or physical care. The choice to provide for their nuclear family or for the parents becomes the dilemma.

An interesting finding in this chapter was that most caregivers experienced objective forms of burden. Objective burden is known to arise from the worry and concern one has for the care recipient fearing that the care they are providing may not be adequate or optimum. This concern usually stems from the practical factors and hardships that come from the illness that the care-recipient has to allocate finances, time and commitment. The type of burden faced among Malaysian carers was similar to carers in Brazil where burden increased with type of care needed due to worsening levels of frailty (Stackfleth et al., 2012). In Japan, Kuwahara et al. (2001) found that time and commitment were the main predisposing factors for increasing levels of burden among carers of frail older people. Among Canadian caregivers of the older people, financial cost either directly due to cost of care-giving or costs due to loss of income was a significant factor in care-giving burden (Lai, 2012).

Frailty is associated with mild to moderate levels of burden in this study even after considering the cognitive status of the frail older people and the socio-demographic profiles of the caregivers. This is likely because when an individual becomes frail the deficits or the disability they are afflicted with increases in intensity and complexity (Clegg & Young, 2011). The high probability of having a physical, cognitive or emotional impairment among frail older people will complicate the process of care giving further and result in a negative emotional state affecting the familial relationship between the carer and recipient (Chappell & Reid, 2002). The financial support required during healthcare visits, provision of vitamins and supplementation, healthy nutrition and transportation starts to multiply as the older people become frail. The stress of being able to care for their own nuclear family needs while still upholding their obligations to their parents will inevitably be the decision one has to make (Shyu, 2000). When the caregiver is unable to cope further with high levels of burden, the commitment and

responsibility as a caregiver starts deteriorating. A study by Annerstedt, Elmstahl, Ingvad, and Samuelsson (2000) found that caregivers tend to have a 'breaking point' once they reach high levels of burden and are unable to cope with homecare.

The focus of research on care-giver burden previously has been on specific ageing conditions such as dementia (Black & Almeida, 2004), cognitive decline (Shankar, Hirschman, Hanlon, & Naylor, 2014), chronic diseases (Garlo et al., 2010), stroke (Rigby, Gubitz, & Phillips, 2009) and disability (Salama & Abou El-Soud, 2012). However, the available information on burden of care-giving among frail older people is still lacking. This study helps to fill the gap on the burden of care-giving among carers of frail older people and the association between frailty and care-giver burden.

The limitation here was that due to low response rates among the caregiver population in the study the findings could only be generalized to the carers of this sample of population studied. Despite the limitations faced, it can be safely summarized that there is a burden of care-giving experienced by carers of frail older people and it is a perspective that should be factored in when policy decisions are being considered.

CHAPTER 9 CONCLUDING DISCUSSION

It cannot be assumed that the old will inevitably become frail but the process of ageing which includes a gradual diminishment of bodily and social systems can lead to high levels of vulnerability and unpredictability (Baltes & Smith, 2003). It is important to measure this decline in frailty since it has been well established that frailty increases the risk for many adverse health outcomes which has led to numerous studies and expanding body of literature on the subject today. It must be acknowledged that the clinical condition of frailty is relatively new and that an accurate assessment tool of this condition is still ongoing. It is therefore not surprising that there are still so many conflicting ideas and grey areas that plague the frailty research.

Despite the uncertainty, researchers and geriatricians globally have made so much progress with their concerted efforts in understanding and mapping this concept in association to ageing. Keeping in par with the mushrooming research surrounding frailty, this research aims to highlight the concern in Malaysia and the health and social care perspectives surrounding it.

In Section 9.1, a summary on the prevalence of frailty and its correlates, patterns on healthcare utilization of frail older people in Malaysia and the burden of care faced by carers of frail older people in Malaysia will be given. In Section 9.2, based on the findings on frailty and its outcomes among the older people in Malaysia several recommendations for policy change will be made to incorporate the screening of frailty as a measure to address ageing issues in our population. Section 9.3 addresses the limitations of this study and the improvements that can be done. Section 9.4 will highlight future research directions that can be taken to add to the strength of this research. This will end with a conclusion of this study in Section 9.5.

9.1 Summary of findings

While frail older people may be a minority in their own cohort, they have been represented as a majority of the consumers within the health and social system today. Frail older people are at risk for negative outcomes in health which in turn present challenges in terms of continuity of care, resource allocation and sustainability of services in both the health and social settings. Innovative and targeted solutions at the clinical and policy level are needed to identify the population at risk of frailty to promote healthy ageing.

9.1.1 Burden of frailty in Malaysia

From Chapter 6, we gain an insight onto the frailty levels we have in Malaysia today. Although the prevalence of frailty in Malaysia is not as high as some countries globally, the knowledge of a large percentage of older people who are pre-frail has to be considered as a pertinent issue that will affect our older people in future.

Looking at the demographic trends in Malaysia (Chapter 1, Section 1.1) it has been projected that Malaysia will reach an ageing nation status in the next two decades. The growth of the population aged 60 and above has continued to show an increasing trend (Department of Statistics Malaysia, 2005) and assuming this prevailing trend persist the absolute numbers moving into the ageing cohort will be high. The condition of frailty is known to increase with age (Rockwood et al., 2004; Roman Romero-Ortuno & Kenny, 2012). With the increasing lifespan seen among men and women in Malaysia, it is inevitable that the proportions of older people transitioning from the state of robust health to, frail will occur. However, knowing that this transition in frailty is gradual and has a chance for reversal or retardation in its biological process provides a golden opportunity for screening and intervention.

In Malaysia, the cut off age for an older person is the age of 60 which marks the end of their productive life years for employment. If the government decides to increase the retirement age to 65, the ratio of older people in the frail category as compared to pre-frail will increase due to increase in prevalence of frailty seen in advanced ages (Roman Romero-Ortuno & Kenny, 2012). This issue is important as the decision on the type and amount of resources to allocate for the frail older people needs careful planning. This also means that the group of older adults aged 60 to 64 are now not seen as older people and are considered as a productive group which would raise new issues such as decrease the number of care-givers in that age group and the need for them to maintain a healthy and productive life till they retire.

Lessons from developed countries like Canada and United Kingdom show that increasing lifespan as a result of improvements in the health and care system does show that older people tend to be more active and independent (Spijker & MacInnes, 2013) but does not necessarily mean people living with complex co-morbidities, disabilities and frailty will decrease (Ruth E. Hubbard, Andrew, & Rockwood, 2009; Oliver, Foot, & Humphries, 2014). Therefore, it would be best if measures are taken to identify frailty in a community and the determinants that contribute to its evolution to allow appropriate interventions to be implemented to prevent or delay the transition of frailty.

Many of the determinants found in this study such as having a history of previous falls, upper and lower body strength and poor perception of one's own health status, have shown significant associations to the evolution of the frailty process and are preventable or modifiable. These preventive modifications can be initiated from the primary care level.

The philosophy of primary care medicine encourages a patient centred approach that takes into account individual goals of care, patient's beliefs, preferences, social context

and patient's experience of illness (American Academy of Family Physicians, 2013). As such, the concept of frailty would allow the expansion of these core skills. Adopting the concept of frailty in primary care would allow early identification of patients at risk and who are moving in and out of the continuum (Lacas & Rockwood, 2012).

As researchers have characterized frail elder population, the observed changes in functional performance and biomarker distribution are distinct from the corresponding age-related changes observed in the healthy old individuals (Fedarko, 2011). Frailty has been shown to be an independent marker for poorer outcomes post-operatively (N. A. Brown & Zenilman, 2010) and on discharge, increased readmissions and increased mortality risks in cardiovascular events (Singh et al., 2008). Recognizing frailty has shown to improve clinical outcomes and improve healthcare costs (Monteserin et al., 2010; Pulignano et al., 2010).

The particular array of services appropriate for a frail individual will depend on his or her specific needs for support with activities of daily living (ADLs), instrumental activities of daily living (IADLs), health problems, sensory changes, mobility, cognitive decline, or general physiological changes (Wolf, 2001). Therefore, it is extremely important to realize that in order for targeted manpower and financial resources to be planned and implemented for the older people we need to understand the essence of the frailty syndrome and its determinants.

9.1.2 Healthcare utilization patterns among frail older people

Frail older adults potentially require a constellation of health services. These services range from inpatient hospital services which concentrate on acute and serious illness and injuries to outpatient care primarily addressing non-emergent acute and chronic health conditions (Young, 2003). Similarly, we do see an increase in healthcare

utilization (for acute and chronic needs) among the frail and pre-frail older people as compared to robust older people in this study as described in **Chapter 7**.

Findings from retrospective Medicare data in the United States show that the trajectory of frailty was a slow decline with a steady progression towards disability before dying from complications of diseases in old age (Lunney, Lynn, & Hogan, 2002). A study involving 10 European countries showed that frail older people were found to increase their primary and hospital care utilization before the onset of disability (Ilinca & Calciolari, 2015). In this study, there was a preference for public healthcare services as the level of frailty increased and if this preference for health provider continues the government may be looking at a high economic burden in the future should an increase in pre-disability utilization happen as seen in Europe.

Healthcare costs have been and will continue to steadily rise to meet the changing health needs caused by shifting burden of illness towards chronic disease and longer lifespan (Erixon & van der Marel, 2011). In middle income countries like Malaysia, which is already hard pressed to provide all curative and preventive health needs through their publicly financed healthcare system will likely face increased pressure due to these escalating costs.

The fee posed at government facilities in Malaysia is a flat RM1.00 for general primary care and RM5.00 for specialized care which is well below the cost of care and highly subsidized (Shepard, Savedoff, & Phua, 2002). It is evident that Malaysians opt for the highly subsidized public healthcare services in Malaysia due to affordability issues involving expensive private insurance (Safurah, Kamaliah, Khairiyah, Nour Hanah, & Healy, 2013). Adding to the affordability lens is the ability of Malaysians to by-pass the primary care system to directly obtain secondary care services leading to inappropriate utilization.

This universalistic subsidized environment of public healthcare services in Malaysia is something that most Malaysians are accustomed to since Independence hence making it a choice of healthcare by default (C. K. Chan, 2014). There has been initiatives by the Malaysian government to look into possible avenues to establish a suitable, appropriate and acceptable national health financing scheme to cope with the rising health expenditures (Hamid, 2nd February 2010; Merican, Rohaizat, & Haniza, 2004). The concern here would be that with this ingrained norm of not paying much for health or medical care, most of our older people might have inadequate protection of financial risk in the future against ill health if the public subsidy is withdrawn. Frailty has been shown to have a large impact on driving up healthcare costs (Kristensson, 2008; Stanton, 2006). Acknowledging that frailty is almost always a consequence of ageing indicates that nations with health systems failing to afford adequate financial protection for their senior citizens are heading for difficult times ahead.

Accessing healthcare services for further diagnosis is the main reason given by the frail subgroup and with the large numbers overcrowding the public health system, the delay in further diagnosis is inevitable. This is a grave concern especially for chronic illnesses requiring early diagnosis such as cancer where one may have lost their window of opportunity. Longer waiting time and longer gaps in appointment have been the trend in most public hospitals in Malaysia as evidenced in a study done by D. I. Pillay et al. (2011). The authors conclude that the demand for subsidised healthcare in Malaysia far outstrips the supply and heavy workload, employee attitude and work process, management issues and inadequate facilities in the public sector were contributory factors.

The next best reason given by the respondents in both the pre-frail and frail groups for healthcare utilization was to obtain adequate vitamins and supplementation. Most of

these visits revolved at the primary care level provided by the government and usually at a fraction of the cost of purchasing vitamins or supplements at the pharmacy. These subgroups of older people sway more towards those who are robust and pre-frail and hardly among those who are frail. Frailty with its myriad dimensions and co-existing conditions may result prescription of long lists of medicines and with the tacit knowledge of the risk of poly-pharmacy they may result in non-adherence (J. M. Hubbard et al., 2014). Anecdotal as it may be, the baby boomer generations usually rely on their well renowned grapevine communication to acquire the nutritional supplements to enhance their longevity. In Asia, Western medications are likely to be abandoned for some traditional or herbal remedy which is believed to be highly naturalistic (Mitha, Nagarajan, Babar, Siddiqui, & Jamshed, 2013; Pham, Yoo, Tran, & Ta, 2013).

The Third National Health and Morbidity Survey (2006) reported that the reasons cited for not seeking care despite having the need was mainly due to the perception that the illness was mild (66.2 percent). These findings are similar to the reasons cited by the pre-frail older people in this study. However, 82.7 percent of the frail older people cited transport as their main problem and this is very high as compared to the national figure of 2.4 percent attributing reasons for not seeking care due to accessibility. This suggests that as the frailty status increases the older people are highly dependent on transport as they urgently need to access the healthcare facility, which when the older person is still healthy or relatively less frail they choose to visit a health facility only if the illness is severe.

The New Zealand Health Survey found that between 2011 and 2012, 27.0 percent of their adults aged 15 and above experienced unmet need for primary health care (New Zealand Ministry of Health, 2012). The main reasons given in that survey were inability to get appointments, lack of transport and cost echoing the findings in our study,

however, the age group range was wider in the survey. This then raises the question of who then is responsible to provide transportation. Is it the duty of the government to provide public transport, family to allocate time to bring them or a provision made available by the healthcare providers themselves? B. Rittner and A. B. Kirk (1995) found that most frail older people who relied on public transport were socially isolated or did not have a good support system in the community worsened by the fact that they were crippled by fear in using the public transport system. A study done in North Carolina found respondents who had family or friends who could provide transport had 1.58 times more visits for chronic care than those who did not (Arcury, Preisser, Gesler, & Powers, 2005). This key finding could explain transportation access in this country with majority of older persons still dependent on their offsprings to participate in their health and well-being. Among those who had no transport, 42 percent of them were frail. These frail older people also did not attempt to self medicate making us question if being frail hampered their physical accessibility to care or there was a psychological perspective that hindered their active participation in their health.

A study on perceived barriers to medical care in older adults showed that patients with depressive symptomatology or with chronic conditions were more likely to have barriers to access (Thorpe, Thorpe, Kennelty, & Pandhi, 2011). Older people's dignity and autonomy can sometimes be undermined in the healthcare setting also the diminished optimism in treating them due to poorer prognosis and cost-benefit issues (Stratton, 2005). The sensitivity and vulnerability of older people is a perspective that needs consideration when planning for healthcare accessibility improvements.

Malaysians have been known to have a preference for traditional and complementary practices (Mitha et al., 2013; Siti et al.). A country like Malaysia with its diverse culture and multiethnic communities have their fair share of health beliefs and remedies that

influences the decision on what type of health services would satisfy ones' need. Cultural influences play an important role in this decision to use traditional and complementary services (Traditional and Complementary Medicine Division, 2011). Comparative research on traditional medicine in the international platform found that a pluralistic healthcare system may provide greatest satisfaction and improved outcomes supporting the idea of coalition of several schools of medicine (Burke, Kuo, Harvey, & Wang, 2011). However, in this study none of the older participants cited the use of traditional and complementary practices during the interview.

This study also shows that there is an increasing trend for hospitalization as the frailty status increases. Similar trends of favouring the public healthcare system are also seen in the older population of this study who have been hospitalized.

The Country Health Plan:10th Malaysia Plan 2011-2015 reported that in 2008, while there were more hospitals in the private sector, 78 percent of the hospital beds remain in the public system catering to 74 percent of admissions (Ministry of Health Malaysia, 2010). This clearly highlights the burden in the inpatient services of the public sector. In Malaysia, civil servants and pensioners are eligible for free services in the public sector and this will most definitely sway their choice in the facility. As for workers in the private sector, they do have the choice for opting to utilize the private healthcare system with the key driver for private healthcare accessibility being affordability. Those who opted for private hospitals spent within the ranges of RM500 to RM2000. This shows that a large percentage of the older population may be highly dependent on the government sector for their inpatient services and affordability may be a main determinant in their decision.

The older people in the frail category generally chose the public health facility, and this is significant to the healthcare planning as public hospitals are burdened with longer

queues and longer waiting time and these are a group of people who need immediate and emergent care and may end up as victims of the setting. A large base of evidence shows that frailty increases chances of hospitalization and is in fact an outcome that is researched widely over the last two decades (Boyd et al., 2005; T. R. Fried & Mor, 1997; M. T. E. Puts et al., 2010).

More than half of the older respondents in this study chose public healthcare facility due to the inability to afford care in the private sector. Utilizing private healthcare services would require one to have a medical or health insurance coverage or spend out of pocket. Private insurance coverage among older people is significantly low, and for those who could afford one with their retirement funds may have missed the boat due to age limits or heavy loadings (C. K. Chan, 2007; Kefeli & Jones, 2012). In Malaysia, this is a salient predicament since this will result in almost total dependence of older people on the government to provide sustainable healthcare which is accessible and at an affordable level.

Cost has not been assessed as part of this study however it is safe to assume that with higher numbers of visit and utilization patterns among the pre-frail and frail categories it will influence the healthcare costs. The affordability lens for vulnerable groups like older people is a necessity when planning for healthcare financing mechanisms in a country. The results from this research show that there is a higher healthcare utilization among the frail and pre-frail group as compared to robust older people. There is also a preference for these pre-frail and frail older people to seek care at public health facilities than private likely due to the cost of healthcare in the private sector. The second pertinent finding is that the frail older people who need healthcare services more are not utilizing the facilities available and this unmet need is largely due to inaccessibility due to transport unavailability. This finding deserves a look into the implementation of the

current older people policies to address the accessibility issues in terms of transport provision or home and respite services to enable the older person to obtain the health services that they need and deserve.

With the increasing numbers of older people projected in the next decade, there will also be an increase in the number of frail older people in Malaysia. The burden on the public system to provide care for these frail older people will increase tremendously. Hence, the government should do its best to institute appropriate health programmes and policies to reduce the number of frail older people.

9.1.3 Burden of care-giving for frail older people

This study has managed to weed out an issue that has long been plaguing our ageing horizon. The findings in **Chapter 8** suggest that there is an unrequited concern in the caregiver context in our nation for our older people.

The demographics of care-giving are currently changing globally. While care-giving was mostly seen among women, the proportions of male care-givers are rising today (National Alliance for Caregiving, 2009; Stobert & Cranswick, 2004). It is essential to challenge assumptions that women should and are the sole primary caregivers as just by alleviating the burden of care for the women does not solve the financial issues that are involved in the provision of care (Buchanan et al., 2011). A paper on outcome differences in caregiver burden between males and females found that education and counselling services did not have better burden outcomes in males as compared to females (Y. M. Chen, 2014). Stobert and Cranswick (2004)'s Canadian study found that men are just as likely as women to be involved in caring for and helping older people.

The issue at hand here would be if the primary caregiver and the decision maker is the adult son of the family in many households one could be looking at communication

barriers on private and sensitive issues. In traditional Asian cultures, the fathers' role is primarily to provide material support for the family while the mothers' role is to take care of the children (Detzner, 1999). This culture that has been ingrained from young among the Asian males contributes to the role they take when providing for their older family member.

The concept of filial piety in which the Asian society is deeply immersed as described by Chow (2006) also lends support that the eldest child has the duty and obligation to play the primary caregiver role. Most of those above the age of 20 are likely to be employed and married, and providing devoted time for caring is very difficult. The caregivers above the age of 60 in this study were mostly the dependents own spouse, and it has been previously evidenced that anxiety and depression is part of the experience for the care giver being emotionally bonded to the care-recipient (Matsuu et al., 2000). Establishing an integrated network to provide psychological, financial and knowledge support to both the caregiver and recipient would kick-start a healthy relationship between them and better quality of life for both.

The present study does contribute to the knowledge that disease progression has an effect on caregiver burden and in this instance the state of being frail. This tradition of care-giving which is deeply motivated by commitment is fundamental to our community. The carers of pre-frail and frail older people mainly experience objective burden which stems from the honest intention to provide but unable to meet this responsibility due to competing demands. Responses to care-giving situations vary considerably, depending on the caregiver vulnerability and strength, the demands of the care recipient, social support system, the type and quality of the familial bond, and the caregivers own health (Young, 2003). It has been highlighted that as the level of frailty increases the decision to institutionalize the frail elder increases (Matsumoto & Inoue,

2007). There is also evidence to show that if the extent of family care-giving should decline, there would be an increase in the burden on formal care providing systems (Spillman & Pezzin, 2000). The projected increase in older people in Malaysia especially the frail would require the government to respond with the infrastructure and human resources required if a significant reduction in informal care-giving should occur. The dependency on the welfare division for finances, housing and respite care would increase.

An important finding is that the caregivers caring for pre-frail or frail older people with very specific and individualized care needs are experiencing burden. This study found that frailty did have an association to the burden of care-giving. Those caring for the frail sub-group experience 4.5 times the burden as compared to those who care for non-frail older people. This does not come as a surprise as many studies on care-giving burden for older people have shown that caregivers of older people with impaired function and severity of disease (Kim et al., 2012), physical and mental conditions (Limpawattana, Theeranut, Chindaprasirt, Sawanyawisuth, & Pimporm, 2013) and financial dependence, which are all dimensions of frailty experience increased levels of burden (Brinda, Rajkumar, Enemark, Attermann, & Jacob, 2014).

A study done on integrated care intervention by Janse et al. (2014) for informal care givers of frail older people in Europe did show benefits in reducing burden with support given by the multidisciplinary team which plans and coordinates the care process. However, commitment and funding are glaring issues when an integrated model is considered for implementation.

A systematic review on the effect of caregiver interventions for informal caregivers of community dwelling frail older people identified that respite care, psychosocial interventions (individual and group support), technology based interventions (telephone

and online counselling) show some benefit in the caregivers coping abilities but the effect was small and inconsistent (Lopez-Hartmann et al., 2012). From the evidence on interventions available, there is still no conclusive method to address burden among informal caregivers.

We do know that it is highly impossible for formal care-givers (such as care provided by the formal healthcare sector) to shoulder this responsibility alone and the role of the informal care-givers are much more favoured (C. M. A. Chan, Ng, Chan, & Phillips, 2003). However, a nationwide study in the United States found that there was an increase in proportion of primary caregivers working alone without the support of a formal paid caregiver due to the budgetary constraints these carers faced (Wolff & Kasper, 2006). Since solutions to find a balance between formal and informal care-giving have yet to be established reversing the state of frailty to robust or delaying the transition of healthy older people to a frail state may have some chance of alleviating this burden among caregivers for now.

This study has highlighted the complex nature of healthcare challenges for frail older people that include acute and chronic episodes of diseases, functional disability, importance of nutrition, and the need for support from formal and informal providers to meet their basic needs. Risks for frailty which are associated to poorer health and social support will lead to an emergence of a subgroup of people whose health is marginal and whose lives are in delicate balance.

From this study, we can conclude that the responsibilities shouldered by the government include appropriate management and also decisions on mobilizing the required human and financial resources for necessities as daily care, transportation for healthcare appointments and home maintenance and safety. The large numbers of pre-frail older people in our population and the challenges that can be forecasted provides an impetus

for the government to incorporate the screening of frailty in the community and institute measures for them to reverse or retard the development of frailty further.

9.2 Recommendations for policy

What we have now is an ageing policy in Malaysia that is consistent with healthy ageing and independent living. However, we do have a large number of these older people who are not able to optimize their health status to achieve the mission and vision of the existing policies. This may be due to the accessibility issues, affordability issues and caregiver issues that we have unearthed in this study. Seen in this light, identifying the older person who are in need of essential healthcare services by grouping into their 'at risk of frail' status can help provide the care or services they need to achieve the objectives of National Elderly Policy. Keeping in line with the worldwide demographic shift of ageing profiles, knowledge on the burden of frailty, the factors associated with the syndrome and the short term outcomes such as healthcare utilization patterns and the burden of care giving will help us provide better health related quality of life for our older people.

The policy analysis in **Chapter 3** sets the stage for the importance of understanding issues related to older people in Malaysia. This thesis unravels the gaps that exist in the policies governing the future of our nations' older people and sets a recommendation of a more integrated approach in managing these older people. One of the main reasons for frailty assessment is the ease of administration of both frailty assessment tools at a primary care level which can then assist these grass root doctors to make informed decisions for referrals to geriatricians. Malaysia with its current numbers in geriatric speciality is severely understaffed and to buffer the oncoming ageing demography the support from the primary care physicians will be advantageous. We have seen differences in the healthcare utilization among the frail or those at risk and the burden of

care increasing linearly with level of frailty for these older people. The benefits to classify these older people into different levels of frailty allow targeted resources and intervention to be made making this endeavour worthwhile.

Looking at the process of implementation currently advocated for older people at the primary care level as described in **Chapter 3** it is possible that too many activities that have been planned do not have the perfectly matched resources. The primary care level has older people wellness clinics and clubs designed to facilitate the promotive, preventive, curative and rehabilitative aspects of ageing. However, the ageing problems are not limited to only one disease but a combination of non-communicable diseases, sense organ disease, cognitive issues and more. Most of these conditions are investigated further when screened using individual screening tests such as questionnaires for cognitive assessment or a general physical examination to discern conditions like diabetes and hypertension. The problem arises when a person who is being treated for one disease and seen by the general medical officer in the primary care clinic may not specifically be screened for a separate condition again unless it is symptomatically warranted. This then delays early detection of several conditions which may co-exist in the older person which when treated early may delay the disease progression. Compartmentalizing clinical conditions will not allow a holistic concept of care for these older people. The problems faced by frail older people have highlighted the need for a patient- practitioner relationship that offers personalized and participatory care which looks at patients as a whole. Assigning case managers from the nearest health centres for frail older people who live independently can help to monitor the changes in health, assess immediate needs and provide support and care that is specific to the time of need is an approach which should be considered. There is some evidence that case managed care can reduce hospitalization (Marek, Adams, Stetzer, Popejoy, &

Rantz, 2010) and improve functioning in frail older people as compared to normal care (Hallberg & Kristensson, 2004). Benefits have also been seen in reduction of institutionalization (Eloniemi-Sulkava et al., 2009), reducing need for readmissions and improving caregiver satisfaction (Eklund & Wilhelmson, 2009). At the primary care level, importance of risk stratification, optimizing one's health to withstand an adverse event, and planning health goals for every individual should be given equal emphasis as the continuous clinical care currently provided.

Older people who have been screened for their frailty status fall under three categories; robust, pre-frail and frail. This division of groups will enable activities to be channelled specifically and resources to be optimized. The robust group of older people who are still fit can be empowered to economically provide for themselves by working after retirement if they choose to. They could even volunteer to assist other older people who require assistance by volunteering at community services such as day care centres which provide physical and cognitive stimulating activities and daily care.

The pre-frail group of older people may require more assistance in terms of healthcare accessibility, physical activity programmes and good health promotional activities and this could be incorporated into Elderly Wellness Clubs to ensure maximum utilization. The frail group of people can then be specifically targeted for rehabilitative services that are available at the primary care level. The resources show that the patient load is too high and that ability to cope is really difficult but by knowing the severity of the ageing condition, educated decisions can be made with ease to prioritize and plan services. Transport system could also be geared to provide the assistance to the frail group who need access to the health care centres or hospitals for a fixed kilometre of radius from the hospital or healthcare facility at a nominal fee to ensure ease in accessibility.

The screening of frailty which is championed in this research as a primary care approach will enable to generally divide the older population into three main groups such as the robust, pre-frail and frail or as broad categories of at risk of frailty and robust population. This way the policy framework and the actions required can be divided based on needs such as more preventive services and health promoting services for the robust, preventive and curative services for the pre-frail and curative and rehabilitative services for the frail. In certain context of interventions, frailty may be perceived as those at risk and not. Those at risk likely would require a focussed and integrated approach at managing all factors that put them at risk and for those who are not to maintain and provide a healthy and balanced life delaying their transition into the 'at risk' state. The resources allocated can be targeted and not underutilized as what happens when blanket services are provided for older people in general.

When planning for individual and collective health measures for frail older people, we should consider factors identified here such as cognitive status of the older person, upper and lower body strength, poor self rated health and history of falls. It is also important to identify the frailty status in an older person to plan for resources in terms of the perceived needs in health care utilization to ensure short-comings in the health system can be prevented. The frail status of older people also serves as an important determinant in the burden of care-giving, hence investing in the health and providing support for the care givers is a factor that deserves attention. Ensuring older people benefit from effective healthcare interventions and support services should become a mainstay of the mission and vision of most older people policies. Researching and disseminating this information to healthcare professionals dealing with the geriatric population will create awareness and early measures can be taken to allow the older person to have better outcomes in their ageing journey. Changing individual behaviour

at risk of becoming frail is a multidisciplinary effort and is a difficult task but changing the surrounding policy environment may prove to be more successful in enabling change in older people management.

Krishnapillai et al. (2011) in their review discussed the challenges of translating the older people policies currently available to practice. The public policies for older people care available in Malaysia today maintain the cultural norms and values of Asian tradition which requires the family to play an integral role in aged care. However, societal pressure and expectations are changing in Malaysia for the older people with rural-urban migration of the younger population, changing roles of women from caregivers to wage earners and changes in family patterns into nuclear types. Policies available in Malaysia currently for the older people require scrutiny to ensure these changing norms and values in older people care are factored in for effective implementation (Krishnapillai et al., 2011).

In Malaysia social and respite care services are limited and the publicly funded care is restricted to institutional homes with no caregivers (assessed by a social worker) and private funded homes are those with caregivers who can afford. This leaves a subgroup of older people who have caregivers making them ineligible for public institutional homes but caregivers who are burden financially and emotionally making them ineligible for the private homes. The need for home and respite care services is naturally increasing and a systematic review on respite care for the frail found that there is some evidence of respite having positive effect on carers (Shaw et al., 2009). In Finland, the utilization of social and healthcare services was found to be connected where those who frequently used social care services had improvement in their health status (Kehusmaa et al., 2012). The social care services provided included home care services and institutionalized care. This shows that with provision of adequate support care services

not only improves the health of the older person but in turn will alleviate the burden experienced by the caretaker.

Another perspective that Ong Fon Sim (2001) highlighted is the absence of a social security scheme to buffer the end of years economic burden that will be imposed by healthcare should there be transformation in the welfarist role of the government. This is a crucial issue to address in a policy as the economic perspective needs to be ironed out to provide care not only in curative aspect but also concentrating equally in the preventive and promotive facets.

Since there is no social protection policy available in Malaysia, the protection during the old age is manifested through the national social policy for public assistance largely through cash and kind (Abd Samad & Mansor, 2013). While some older people are protected by formal pension schemes such as government pension plan and private Employees Provident Fund (EPF) Scheme some of the older people are left with inadequate or no financial protection to support the rising cost of healthcare (Mohd, Mansor, & Ku Ahmad, 2014). This is further supported by the fact that there is a rise in the beneficiaries of 'Bantuan Orang Tua' (BOT) from 99,399 older people in 2009 to 152, 138 older people in 2012 (Department of Social Welfare Malaysia, 2012). Frail older people with their concurrent medical co-morbidities and geriatric syndromes are candidates for catastrophic financial consequences are in dire need of a sustainable and sound social security scheme.

Though, Malaysia is yet to reach an aged nation status it is better to be prepared to face the challenges that lie ahead. Advocacy on the importance of savings, collaboration with non-governmental organizations (NGO) on corporate social responsibility (CSR) practices and a universal compulsory saving scheme are some of the pathways that have

been proposed apart from the urgent need of formulating of an overarching policy (Abdul Samad, Awang, & Mansor, 2012).

This is also probably a good time to recognize the need to promote intergenerational understanding through activities and social interactions that have been overlooked in modern industrialized societies. Article 16(3) of the Universal Declaration of Human Rights states that, "The family is the natural and fundamental group unit of society and is entitled to protection by society and the State" (United Nations General Assembly, 1948). In Singapore, the Ministry of Community Development, Youth and Sports took the effort to start a taskforce to promote grand-parenting and intergenerational bonding in 2002 in response to the changing demographic trends they face (Thang, 2011). The mainstay of this intergenerational bonding was to create opportunities for different generations to meet and interact such as initiatives where the youth provides services for the old, mentoring programmes by the old for the young and encouraging age-integrated centres which provide day care for the young and old. Since the multiracial and cultural context that we live in are similar to Singapore, these are measures that can be advocated in our policy change. With the evolution of family dynamics that we see today in middle income developed societies like Malaysia, programs and policies promoting intergenerational solidarity is crucial.

Policy makers are usually keen to find a specific niche to champion their stand on emergent and urgent issues and providing evidenced based information to foster their interest is definitely worthwhile. Most of the policies in this country pertaining older people health are formulated from recommendations provided by internationally recognized organizations and information obtained from experiences of global counterparts but the link that is weak is the translation of this tacit information to match

the needs locally. Identifying the similar burden locally and understanding the web of association would reinforce this final missing link.

It is extremely important to realize that in order for targeted measures to be planned and implemented for the older people we need to understand the essence of the frailty syndrome and its determinants. Many of the determinants that have been studied to date and have shown some association to the evolution of the frailty process are preventable and can be done at the primary care level. In this research, we found falls, muscle strength and self rated health to be determinants that influence frailty. Advocating a policy that incorporates fall prevention services at home and the community can delay the frailty process and in turn delay the morbid outcomes. Another important step in policy change would be to ensure the older person have some form of community based physical activity programmes at their respective housing areas to encourage these older people to become and stay active.

The benefits of identifying frailty are that these older people can benefit from the existing healthcare system and can spur policy makers into making reforms to the system which focus on relevance and effectiveness. However, the risk of defining frailty is that under the guise of "frail and unsuitable patients" these older people may become victims of rationed care due to economic reasons and investing in these older people may be avoided.

The understanding of the concept of frailty is of utmost importance prior to policy change to ensure these risks are averted and to create a more proactive, integrated, person-centred and community-based response to frailty. There have been several initiatives globally to translate research on common geriatric clinical conditions into effective national policies to provide optimal care for patients with geriatric syndromes (M. E. Tinetti, Gordon, Sogolow, Lapin, & Bradley, 2006).

The European Commission in 2014 organized a conference to focus on frailty as a condition of old age and a special focus on identifying priorities for an EU policy acknowledging the importance of screening for frailty in a population (European Commission for Public Health, 2014). On 18th of June 2014, a conference on frailty was held in Brussels where a team of key experts from the European Union (EU) gathered to identify policy actions, recommendations and guidelines to build a coherent policy on frailty (European Commission for Public Health, 2014). In her opening speech during the 2014 Frailty Conference in Brussels, Paula Testori-Coggi, the Director General for Health and Consumers stated that, "Obtaining evidence from datasets and health indicators will enable policymakers make informed judgements on what works and does not work in developing a policy" (Testori-Coggi, 2014). This is the first policy change initiative on frailty that has been done globally.

In the United Kingdom, the National Institute of Health and Care Excellence (NICE) released guidelines on preventing disability, dementia and frailty as part of their initiative to improve the health of their older people which has implications on the individual, health and social care system (Oliver & Buck, August 2014). In Canada, Technology Evaluation in the Elderly (TVN), funded by the Government of Canada's Networks of Centres of Excellence (NCE) program is focused on developing a national strategy to initiate transformational change in health care for frail older Canadians as an initial approach to health policy change for older people (Technlogy Evaluation in the Elderly Network, 2015).

This trend of inclusion of frailty into a policy perspective which is unfolding globally definitely favours the need to screen for frailty in a population. Early detection of frailty will have a positive impact on healthcare spending such as the avoidance of unnecessary

hospitalization, reducing morbidity and complications of clinical conditions and reduction in the social and financial burden faced by caregivers.

Policy making decisions is seldom a straightforward systematic process but rather a blend of science, politics and common sense (Brownson et al., 1997) hence with the knowledge of benefits and risk findings from this study it should be used with care to influence the policy makers to develop more comprehensive strategies for the older people health and well-being. The role of public health in prevention of long term ageing conditions, policies on health and social care have been left to develop in their silos for too long. Integration cannot just be about treating frail older people, we need to think beyond individual outcomes and incorporate healthcare, social care, infrastructural changes, employment opportunities and families as part of that change which can be done through a sound and grounded policy.

The next step forward is to incorporate frailty in our policy by instituting several measures:-

a) Training and sensitizing healthcare workers in primary on frailty and the tool to measure, ensuring the policymakers understand the cost benefit of preventing frailty in comparison to healthcare and socialcare expenditures related to ageing conditions. Nurses can be trained in post basic courses specific to geriatric care to reduce the gap of insufficient geriatric specialists.
b) The older persons in the community have to be empowered with the information of available facilities and providing accessibility (the nearest health clinics)
c) Classifying older persons into the various frail categories such as robust, pre-frail and frail
d) Ensuring all the older persons categorized as pre-frail are under a regular follow up and addressing all health conditions which contributed to their frail status-

with referrals to the respective specialists, serial blood or physiological check-ups to monitor changes and recruiting them into the wellness club to share and empower them with information and updates

e) Facilitating physical exercises programmes suitable to each individual after being assessed by an occupational therapist

f) Providing adequate supplementation and nutritional counseling.

g) Once the system is created to ensure a good database is in place to monitor their progress or detect their regression early to address the factors contributing to frailty

h) The numbers of geriatricians should be increased gradually and encouraging family medicine specialists to take up a subspeciality in geriatric care.

i) It is also imperative that indicators of change such as improvements in frailty score, reduction in comorbidities, numbers actively participating in health and wellness programmes should be monitored so that effective health promotion activities can be done to encourage participation from the older persons.

j) Adequate tax breaks for caregivers with dependent older persons or provision of health insurance as a safety net for old age should be done.

9.3 Limitation and Improvements

Conducting this research involving community dwelling older people from an urban setting had its fair share of challenges. The data sampled by the Department of Statistics, Malaysia was from the 2010 Census and approximately 20 percent of the sampled population were not residing at the given address any longer. Conducting research as close to the census date could increase this probability or coordinating health based research during the census period could increase the representativeness of the sampling frame. The numbers of caregivers that participated in the research was

rather low as the study was conducted during the day when most of them would likely be at work. There was also resistance from caregivers to allow entry into the homes in some cases due to security reasons. It would be better to conduct this research on weekends or after working hours to maximize the response rate however, the security and safety of these households should be taken into consideration. Some of the caregivers chose not to participate in the research even though their older relative voluntarily consented. They gave reasons as not being comfortable with research from the government. Good advertising and information with the support of authorities and the government prior to the commencement of the research will help in establishing trust and willingness among the participants.

A novelty in this research is that to date there have been no normative values that have been consensually established to date to define frailty in Malaysia. As only a comparative analysis from other studies could be discussed, hence the age independent cut-offs as suggested by Song et al. (2010) was used. The values used and obtained in this research could be used as a pilot for other frailty based research to allow for a consensus in the future.

Even though the magnitude of the findings is not immense, we do have a significant findings in the context of healthcare utilization among the older people especially those who are frail. The outpatient utilization data is self reported and is subject to recall bias, but with the results that have been highlighted in this study it definitely merits the need for further work in this context. The efforts to minimize recall bias was done by obtaining outpatient records for those who attended government clinics, appointment cards and receipts of payment at the health facility. The results obtained in this study were also compared to the utilization results obtained in the National Health and Morbidity Survey to look for any glaring differences.

The results though showing frailty as a significant predictor of care giving burden the power of this study is rather limited as there was a small sample of population who were categorized of frail. This association might have been underestimated with the poor response rate of caregivers which does considerably influence the outcome hypothesized. It is expected that to access the care-givers in this district is something of a feat as Johor Bahru with its close proximity to her neighbouring sister nation, large numbers of the young adults (usually the care-givers) are employed across the border in Singapore. However, the results from the pre-frail group did show significant findings which would help in further research on caregiver burden.

The data and findings obtained in this population has to be generalized to the population in other states in Malaysia with caution as the mean monthly gross household income varies by ethnicity, urban-rural strata and state (Department of Statistics Malaysia, 2013). However, with urbanization rates in Johor Bahru rising to meet the 100 percent urbanization goal by 2025, the findings here reflect other highly urbanized cities in Malaysia.

As a cross-sectional study a further limitation is that we are unable to establish a direct causal relationship between the correlates and frailty status but it did highlight factors that did have some influence on frailty which serves as a foundation for further research. Longitudinal studies are needed to further confirm this relationship. This population based study supports the strength of our findings to the Malaysian population however it cannot be generalized to other ethnic groups from similar middle-income countries.

This research with its limitations serves as a foundation for further work in the field of frailty, healthcare utilization and caregiver burden among the community dwelling older

people in Malaysia and examining this concept holistically over time would give us a more vivid picture of frailty in Malaysia.

9.4 Future research directions

An issue that was not investigated in this study was to find a frailty assessment tool that best measured the concept of frailty. The British Geriatrics Society has established that the gold standard for the management of frailty today is by using a holistic, multidimensional, inderdisciplinary assessment of an individual known as the Comprehensive Geriatric Assessment (CGA) (British Geriatrics Society, 2014). Therefore, it would be valuable to assess the older respondents in this study using the Comprehensive Geriatric Assessment (CGA) by a clinical geriatrician to identify which frailty assessment tool gave the best concurrent validity to demonstrate the level of frailty in an individual. However, the feasibility of conducting such a research has to be considered with the limited numbers of geriatricians in Malaysia.

Looking at the pre-frail levels that are high in this population, the need to institute and evaluate frailty reversal interventions is highly needed. Frailty reversal interventions such as fall management, coordinated physical and/or cognitive activities or nutritional advice to improve muscle strength and functioning are some of the interventions that can be tried to understand what works best for this community. Monitoring the increase or drop in their frailty scores can help guide the intensity and continuity of the intervention. Assigning case managers to provide individually tailored programmes for frail older people is a novel way of approaching frailty since we know that there are multiple aetiologies that make a person frail.

We did acknowledge the complexity of measuring frailty and the impact of prevalence measured using various tools. It would be worthwhile to follow up the current cohort of

older people over a long duration to identify the various short and long term outcomes to understand the predictive validity of both tools in the Malaysian population. This will help both the clinicians and the policymakers on the most appropriate tool to measure frailty in the Malaysian population based on the outcome of interest.

Within the context of growing pressures to bring down healthcare costs, it would be interesting to conduct longitudinal studies to predict accurately the significant difference in the utilization patterns and the impact on the costs by these frail older people. Conducting research on comparing effectiveness of interventions and cost-effectiveness of these interventions will potentially help slow the growth of health care spending among the older people. However, to ensure that the data is more robust a total information system collecting utilization and cost data is required enabling better decisions to be made for these frail older people.

An important scope highlighted in this research was that there was a barrier for healthcare utilization among the frail and pre-frail older people in Malaysia. The lack of transportation seemed to be the primary issue for not accessing a health facility, so different transportation initiatives to the nearest healthcare facility could be researched to discover the best form of transport system to avoid inaccessibility. A qualitative study involving the reasons for underutilization is a scope that further research could be undertaken. Involving the caregivers in focus group discussions to understand what type of help they need and prefer to optimize care for their older people would enable decisions that are more targeted and appropriate.

From this research we know that caregivers experience an objective form of burden and caring for the frail does play a role in this burden. Providing training for these caregivers on time and financial management, creating support groups from local educational institutions and looking into provision of respite care would be a form of

intervention strategy to alleviate the burden of care-giving. However, more research is needed on the most appropriate type of respite delivery, content of training manuals and the economic and social consequences these interventions result.

9.5 Conclusion

The findings in this research have given an insight on the frailty status and correlates among the Malaysian older people. The study also found that there are increased patterns of healthcare utilization among the frail and they also have unmet needs in utilization of healthcare services. There is also an increase in burden experienced among carers of these frail older people with frailty having a strong association to caregiving burden. Though our frailty levels are not as high as some countries globally, the pre-frailty levels that are elevated herald an unpredictable and bleak future for these older people if action is not taken.

The ground work in this study may provide a stepping stone for work done in Malaysia on frailty and older people health issues so that it may steer stakeholders involved in older people care and services toward a more informative path and to assist them in making conscious and evidence based decisions.

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LIST OF PUBLICATIONS AND PAPERS PRESENTED

Type	Title	Journal/Venue	Status
Publication	Frail Older people in an Urban District Setting in Malaysia: Multidimensional Frailty and its Correlates	Asia-Pacific Journal of Public Health	Published
Paper presentation	The care giver burden among community dwelling older people in Malaysia	National Geriatric Conference, Malaysia	Awarded best oral speaker – 1st prize
Paper Presentation	Caregiver burden of frail older people in an urban district in Malaysia	Asia- Pacific Academic Consortium of Public Health Conference, Malaysia	Oral presentation
Paper Presentation	Screening for frailty among older people to allow targeted health promotion and intervention in Malaysia	4th Asia Pacific Conference of Public Health, Malaysia	Oral presentation
Paper presentation	Multidimensional or physical frailty: Frail Older people in an Urban Primary Care Setting in Malaysia	International Conference on Frailty and Sarcopenia Research, Barcelona, Spain	Poster presentation