

Palliative Care Needs Assessment

Malaysia



Contents

DEFINITIONS BY WORLD HEALTH ORGANISATION	01
Palliative Care	01
Palliative Care for Children	01
ESTIMATION OF PALLIATIVE CARE NEEDS	05
Estimation of Palliative Care Needs in Adults	05
Estimation of Palliative Care Needs in Children	07
Causes of Death in Adults in Need of Palliative Care at End of Life	09
Causes of Death in Children in Need of Palliative Care at End of Life	10
OVERVIEW OF PROVIDER CHARACTERISTICS	12
Mapping Palliative Care Services	12
Defining Levels for Malaysian Palliative Care Services (PCS)	14
Background on Community Palliative Care Services in Malaysia	16
Mapping Levels of Malaysian Palliative Care Development	17
Challenges and Barriers to Community Palliative Care Service Development	21
PUBLIC AWARENESS SURVEY SUPPORTS A PUBLIC HEALTH MODEL FOR PALLIATIVE CARE	24
Results of Public Awareness Survey	24
A. Health Status and Health Care Seeking Behaviour	25
B. Thoughts and Preference Regarding End-of-Life	25
C. Knowledge, Attitudes and Expectations towards Palliative Care	27
DISCUSSION	33

Abbreviations

AIDS	Acquired Immunodeficiency Syndrome
CLS	Chronic disease of lifestyle
CSMFs	Cause-specific mortality fractions
EOL	End-of-Life
HIV	Human Immunodeficiency Syndrome
IHME	Institute for Health Metrics and Evaluation
JPN	Jabatan Pendaftaran Negara/ National Registration Department
MOH	Ministry of Health
NCDs	Non-communicable diseases
NCSM	National Cancer Society of Malaysia
NPO	Non-Profit Organisation
PCS	Palliative Care Services
PHM	Public Health Model
PHS	Public Health Strategy
ROC	Registrar of Companies
ROS	Registrar of Societies
WHA	World Health Assembly
WHO	World Health Organisation

List of tables & figures

Table 1:	Estimated Need for Palliative Care at the End-of-Life for Adults in 2012 using the WHO Approved Method	06
Table 2:	Estimated Need for Palliative Care at the End of Life for Children in 2012 using the WHO Approved Method	07
Table 3:	Basic Indicators	08
Table 4:	World Palliative Care Association (WPCA) Categorisation of Country Level Palliative Care Development, 2011 (N=234)	12
Table 5:	Typology used for Mapping Palliative Care Services in Malaysia	14
Table 6:	The number of PCS in Malaysia based on Levels of Development (n=26)	18
Table 7:	Hospices, Population, Population Density and estimate of patients Requiring palliative Care in each state/FT inMalaysia	20
Table 8:	Demographic Profile of Participants (n=600)	24
Figure 1:	Public Health Model for Palliative Care Development	03
Figure 2:	Malaysia's Population Structure, 2000 and 2010	09
Figure 3:	Causes of Death in Adults Needing Palliative Care at EOL	10
Figure 4:	Causes of Death in Children Needing Palliative Care at EOL	10
Figure 5:	Mapped Location of PCS in West Malaysia (n=18) and East Malaysia (n=8)	19
Figure 6:	Challenges Faced by Community PCS (n=18)	22
Figure 7:	Thinking of the family member who passed away, which of the following best describes their end-of-life experience? (n=600)	25
Figure 8:	Respondent's preferred place of death and where they expect to receive the bulk of their care (n=600)	26
Figure 9:	Influencing Factors of why People Die at Hospital despite a preference to die at home	26
Figure 10:	Reasons why respondents think people might be reluctant to discuss EOL care	27
Figure 11:	What term would you associate with this type of care? (n=600)	28
Figure 12:	To the best of your knowledge, does palliative care include any of the following? (n=600)	28
Figure 13:	Support for palliative care approach	29
Figure 14:	Agreement with Statement about Palliative Care	30
Figure 15:	In your opinion, who should be paying for palliative care?	31
Figure 16:	Expectations from Care Providers for Palliative Care	31

Authorship & acknowledgements

Written and edited by:

Dr Winy Yeap Sekhar, Research Unit, Hospis Malaysia

Dr Stephen Connor, Executive Director of the Worldwide Hospice Palliative Care Alliance

Dr Sylvia McCarthy, Medical Director, Hospis Malaysia

Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia

The authors and editors would like to thank the following:

Fatia Kiyange, Programmes Director, African Palliative Care Association

Sharon Chuah, General Manager, Dynamic Search Sdn Bhd

Lim Tuck Sun, Partner, Chooi and Company

Hospis Malaysia Advocacy Team

Foreword

Hospis Malaysia was founded on a vision to provide the highest quality of palliative care to all in need. In the past 25 years, we have developed the largest community palliative care service in the country; provide a strong education and training programme and increasing public awareness of palliative care.

When palliative care was formally introduced in Malaysia in the 1990's, there was no framework to support the development of this fledgling medical speciality. Charitable community services helmed by well-intentioned volunteers subsequently aided by the Ministry of Health, gradually developed services in the country.

However, it is important to pause and reflect on the challenges ahead. Thus, over the past year, we have embarked on several areas of work to gauge the needs for palliative care in the country. Using a World Health Organisation (WHO) framework, we have estimated the need for palliative care in the country. A public survey was completed to see how Malaysians reflect on the possibility of being affected by life limiting illness. And finally we have attempted to assess the care structure provided by the various community services in the country.

These studies are important as it allows both the Ministry of Health and palliative care services to plan their policies, training and services to best serve the country.



Dr Ednin Hamzah
Chief Executive Officer, Hospis Malaysia

Executive summary

In 2014 Malaysia was a co-sponsor to a WHA resolution calling for member states “to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes” Palliative care services have existed in Malaysia for the last 25 years starting with volunteer organisations providing care in the community. It has been recognised as a medical subspecialty since 2005.

This report presents three sets of data collected by Hospis Malaysia in 2015 to form a basis for discussion and action about the direction of palliative care development in Malaysia.

- **National Level:** Estimation of End-of-Life and Children’s Palliative Care Needs in Malaysia using a WHO framework.
- **Provider Level:** Overview of Community Palliative Care Services
- **Community Level:** Public Awareness, Perception and Expectation of Palliative Care

The key findings are:

The estimated number of Malaysians requiring palliative care is 56,000 yearly. Non-communicable diseases (NCDs) are the top causes of death in adults needing palliative care, with cardiovascular diseases (43.8%) overtaking cancer (32.7%) as the main cause. Others are chronic obstructive pulmonary diseases (COPD), diabetes mellitus, HIV/AIDS, kidney diseases and certain neurological diseases such as Parkinson’s and Alzheimer’s.

The overview of community palliative care services shows community services run by NGOs are limited to the major cities. However, from information provided on caseloads by these services, we were able to estimate that only 8.3% of the country’s palliative care needs are being met (no estimates were available from palliative care units in hospitals). From the information available about staffing, we have tried to infer the level of care provided by the various community services.

The level of care they are able to provide is not adequate to deal with the predicted need. From the Public Awareness survey, although awareness of the term palliative care and service availability is low the public is concerned about end of life issues. More than half the population (53 %) lives with someone with a chronic disease.

They would like their care to be in the community (53%) where possible and they would prefer to die at home (61%). However, only 31.8% have a regular family physician. From their experience of deaths in the family in the last 10 years (60% of those interviewed) most deaths (51%) occurred in hospitals. When they are given some information they agree that palliative care is important and should be available to everyone in need.

They also think that talking about end of life care preferences is important 65.7%, more so as they get older. However many do not for fear of upsetting others (89%). The second commonest reason for not talking about end of life preferences was “nothing I can do about it, so why bother” Most do not know what services are available or the type of care they might expect at the end of life.

Recommendations

The needs analysis reveals that emphasis on palliative care on cancer needs to shift and services need to develop to include patients with other life-limiting diseases. There is also a need to recognise that children also suffer from life-limiting illnesses, and will require palliative care. There has to be a shift to cater for increasing numbers of patients with non-communicable diseases. This will require the engagement of health care professionals in diverse specialties and general practitioners through education and training.

The way health care is delivered and where it is accessed also needs to be addressed. The public awareness survey shows that the public would like to be cared for in the community but still view hospitals as the only place where they can receive pain and symptom management. However community services are limited. Cancer pain guidelines and palliative care symptom management guidelines have been written but need to be more widely disseminated. The standards of care patients can expect should be defined so that community palliative care organisations can look to develop to provide a consistent level of care across the country.

At the same time there needs to be a drive to increase awareness and to encourage dialogue with the public around palliative care and end of life issues. Initiatives to improve palliative care need to be coordinated through a national policy and structure, which includes all stakeholders. This includes the Ministry of Health both representing hospital and community services, Ministry of Education, community palliative care providers and most importantly the patients and families affected by life threatening illness. This National Policy should be both transparent and accessible to all stakeholders.

A Needs Assessment of
Palliative Care in Malaysia:
2016

Definitions by World Health Organisation

Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative Care for Children

WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers and even in children's homes. "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

Source: <http://www.who.int/cancer/palliative/definition/en/>

Introduction

This report attempts to provide an overview of palliative care needs in Malaysia based on the definitions by the World Health Organisation (WHO) above. It is hoped it will serve as a point for discussion about how to move forward in developing palliative care services. Data was collected in three parts:

- **National Level:** Estimation of End-of-Life and Children's Palliative Care Needs in Malaysia
- **Community Level:** Public Awareness, Perception and Expectation of Palliative Care
- **Provider Level:** Overview of Community Palliative Care Services

When palliative care first started, it was out of a sense that patients with life threatening illness were being abandoned after cure was no longer an option. These patients were suffering and palliative care was a humane response to their needs. From the start, the early palliative care pioneers recognised the need for research to inform their approach to patients' symptom management, psychological and spiritual needs. In recent years an evidence base has grown which shows that quality palliative care can improve quality of life and reduces unnecessary, futile and aggressive medical interventions at the end of life^{1, 2}. Most recently a landmark study showed that good palliative care actually prolongs life³. The WHA resolution in 2014 co-sponsored by Malaysia called for member states:⁴

“to develop, strengthen and implement, where appropriate, palliative care policies to support the comprehensive strengthening of health systems to integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes”;

WHO provides a public health model for the development of palliative care, which serves as a useful guide.

‘A Public Health Strategy (PHS) is an approach to transfer knowledge and skill into cost-effective interventions which can potentially reach the population through collective and social action.’

WHO recognised an unmet need for palliative care for the millions of cases of death annually from chronic illnesses, cancer and AIDS, and that this need will continue to grow with the aging of the global population. Using a PHS, WHO in 1990 pioneered a public health model as a guide for countries to integrate cancer and palliative care into existing health care systems. Stjernswärd, in his article “The Public Health Strategy for Palliative Care”, represented this in [Figure 1](#), showing the various factors that determine development. Namely, 1) supportive policies backed by adequate funding, 2) access to medicine, 3) education in the form of public awareness and professional & caregiver training, and 4) implementation of services⁵. Under each of the above four components, Stjernswärd has described in further detail.

Figure 1: Public Health Model for Palliative Care Development



Since then, there has been increasing recognition of palliative care as a public health issue, with countries integrating it into their healthcare system at all levels. For instance, in Norway tertiary or regional centres, conduct education, research, and audit, and support authorities with planning, in addition to serving hospitals and communities; Secondary centres, in smaller hospitals have consult teams, and or inpatient units, and outpatient clinics; At primary care level, family practitioners and palliative care units provide palliative care at homes and in nursing homes.⁶

This public health model links the community to promotive health services in order to improve the quality of EOL by managing pain and other physical symptoms, and addressing psychosocial needs. It promotes healthy behaviour by educating and empowering the community to make informed decisions. This approach differs from acute medical models, which are designed more to respond to emergencies, exacerbation of a chronic illness, short term stabilisation and surgeries. In addition, acute medical care tends to be more technology driven and dissociative to families and patients' non-medical support systems. Physicians in acute care may also not be prepared to support the psychosocial needs of dying patients and their families. In contrast, community palliative care has been shown to decrease health care cost, decrease pressures on hospital and ICU beds, and improve patient outcome⁷.

In the recent World Health Assembly 2014, this PHM is further reaffirmed in a WHA Resolution (WHA67.19) titled “Strengthening of palliative care as a component of comprehensive care throughout the life course”. WHA urges Member States to assess needs, and develop, strengthen and implement policies, and resources (human resource, financial and medicine) in order to *“integrate evidence-based, cost-effective and equitable palliative care services in the continuum of care, across all levels, with emphasis on primary care, community and home-based care, and universal coverage schemes”*⁴.

First introduced in Malaysia in the 1990’s, the awareness, perception, integration, and delivery of palliative care is still at an early stage and is not clearly defined. The first palliative care services were established by charitable organisations providing care in the community. Since then MOH has recognised palliative care as a medical specialty and started to develop services in hospitals. Whilst there are different perceptions of palliative care, the MOH views it principally as a hospital based service, relying on NGO’s to provide community services⁸. In order to inform future direction and development of services, more data is needed about palliative care needs and the extent and level of services available to address these needs. Hospis Malaysia therefore commissioned an estimate of palliative care needs. We also tried to map the current availability of palliative care in the community.

Palliative care, at its core value, is patient centred whole person care and, in planning any services, it needs to be developed and planned with input from patients and families. The public awareness survey is the third part of this report and serves to provide an insight into the public’s awareness of palliative care and also gives insight into their current experience of chronic illness and end of life care and the kind of care they want.

The aim is to look at trends in the growth of demand and delivery of palliative care services, identify gaps, and provide a baseline from which to define quality standards for palliative care services. There are data limitations to this study, which will be highlighted in order for the report to be read in context. However, this is a first step to look at perceived needs of community palliative care.

Estimation of Palliative Care Needs

This part of the research was conducted by Dr. Stephen R. Connor, Senior Fellow to Worldwide Hospice Palliative Care Alliance. Using a WHO approved method from the *Global Atlas of Palliative Care at the End of Life, (2014)*⁹, and WHO mortality data. As population based mortality data in Malaysia is not available, hospital mortality rates were used to derive cause-specific mortality fractions (CSMFs) and in turn, these fractions are used to estimate population mortality rates. This is a validated method published in 2007, and developed by researchers at the Institute for Health Metrics and Evaluation (IHME). It allows for countries with incomplete death registration data to estimate causes of death in their population based on hospital mortality data¹⁰. A list of disease categories requiring palliative care at the EOL is determined and pain prevalence is used as a function to determine the total number of patients requiring palliative care at EOL¹¹.

Estimation of Palliative Care Needs in Adults

In Malaysia, when deaths occur in a medical facility, a death certification (JPN.LM09) is issued by a medical practitioner with a cause of death. However, when deaths occur outside hospitals, a report is made by taking the deceased's documentation (identification and medical) to the police station. If there are no suspicious circumstances the death registration/burial permit (JPN.LM02) is issued which does not necessarily contain a cause of death. Under suspicious circumstances or if the deceased is young, the body is taken to a hospital where examination/autopsy is done before a post-mortem (JPN.LM10) certificate is issued. The JPN forms, together with identification documents, are taken to the National Registration Department where a Death Certificate is issued.¹². In the Death Registry, the cause of death is therefore not complete, and in order to estimate population mortality data (A) in [Table 1](#), CSMFs derived from hospital mortality data for 2012¹³ as described under method above was used. As not all people dying from these disease categories require palliative care, pain prevalence (B) is used as an indicator for palliative care needs (C).

Table 1: Estimated Need for Palliative Care at the End-of-Life for Adults in 2012 using the WHO Approved Method

Disease categories/groups requiring palliative care at the end of life	Total Deaths from diseases requiring palliative care at the end of life Numeric (A)	Pain Prevalence at the end of life (%) : B	Patients in need of palliative care at the end of life Numeric: C=AxB
CANCER	21,100	84%	17,724
HIV/AIDS	4,800	55%	2,640
PROGRESSIVE NON-MALIGNANT DISEASES			
Alzheimer's disease & other dementias	100	47%	47
Cardiovascular diseases (excluding sudden deaths)	35,443	67%	23,747
Chronic obstructive pulmonary diseases	6,800	67%	4,556
Cirrhosis of the liver	1,400	34%	476
Diabetes mellitus	4,800	64%	3,072
Multiple sclerosis	0	43%	0
Kidney diseases	2,800	50%	1,400
Parkinson's disease	500	82%	410
Rheumatoid arthritis	100	89%	89
Drug-resistant tuberculosis	24	90%	21
TOTAL PROGRESSIVE NON-MALIGNANT DISEASES	51,967		33,818
Total Adults	77,867		54,182

From the table above, the total number of adult patients in need of palliative care is 54,182, of this, HIV/AIDS, cancer and progressive non-malignant diseases make up 4.9%, 32.7% and 62.4% respectively.

Estimation of Palliative Care Needs in Children

A similar analysis is done to estimate the palliative care needs for children. From the table below, the total number of children in need of palliative care is 2,202 (Table 2). Of these, there are no HIV/AIDS mortality, and cancer and progressive non-malignant diseases make up 14.5% and 85.5% respectively.

Table 2: Estimated Need for Palliative Care at the End of Life for Children in 2012 using the WHO Approved Method

Disease categories/groups requiring palliative care at the end of life	Total Deaths from diseases requiring palliative care at the end of life Numeric (A)	Pain Prevalence at the end of life (%): B	Patients in need of palliative care at the end of life Numeric: C=AxB
CANCER	400	80%	320
HIV/AIDS	0	80%	0
PROGRESSIVE NON-MALIGNANT DISEASES			
Children			
Cardiovascular diseases (excluding sudden deaths)	134	67%	90
Cirrhosis of the liver	0	67%	0
Congenital Anomalies (excluding 50% heart anomalies)	1,050	67%	704
Endocrine, blood, immune disorders	1,000	67%	670
Meningitis	100	67%	67
Kidney diseases	0	67%	0
Protein energy malnutrition	0	67%	0
Neurological conditions (excluding epilepsy)	100	67%	67
Neonatal conditions (see formula for excluded conditions)	425	67%	285
Total PROGRESSIVE NON-MALIGNANT DISEASES	2,809		1,882
Total Children	3,209		2,202

In total, the estimates of patients requiring palliative care for 2012 is 56,384, with children accounting for 3.91%, and adults comprise 96.09% of cases.

To put the data above in context, Table 3 provides some basic population data. In 2012, Malaysia's total population is just over 29 million. The life expectancy is 74.8 years (rank 85), with a low under-5 mortality rate of 9 (rank 141), and an even lower mortality rate of 4.7 (rank 200).

The low mortality: life expectancy rank reflects a relatively young population, but as the youth bulge progressively ages^a, dependency ratios^b and mortality rates will increase putting increasing pressures on families and the health care systems. With the relatively young population structure as reflected in [Figure 2](#), we have the opportunity to develop and plan for palliative care services which can cope with the anticipated future pressures.

Putting the two data sets together, for the year 2012, the total number of deaths in Malaysia is 136,835¹⁴, of which, from our estimates, 81,076 deaths are from disease categories requiring palliative care, and of these 56,384 patients needed palliative care. This equates to an estimate of 6 out of 10 deaths in Malaysia are from chronic diseases (malignant and non-malignant), and 4 out of 10 deaths are of patients who will benefit from palliative care. Take note that in our analysis, our assumption is that pain, being the most common symptom, is used as an indication for palliative care needs, whilst chronically ill patients without pain have been discounted from this estimate. In addition, the mortality driven figure does not take into account patients who are ill and not dying, who may still benefit from palliative care.

Table 3: Basic Indicators

Basic Indicators (Year 2012)	
Total population	29,239,900
Total number of deaths	136,835
Life expectancy at birth (years)	74.8
Life expectancy rank	85
Under-5 mortality rate (per 1,000 live births)	9
Under-5 mortality rank	141
Crude death rate (per 1,000 population)	4.7
Mortality rank ^c	200

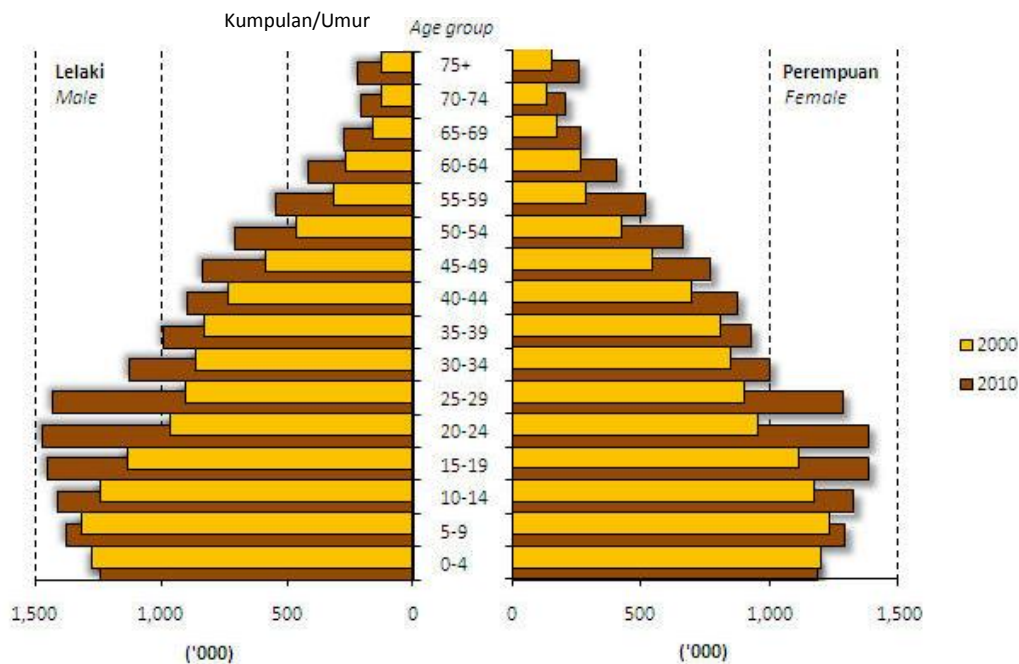
^a <http://www.worldlifeexpectancy.com/malaysia-population-pyramid>

^b Refers to the ratio of the number of persons below the age of 15 years and the number of persons aged 65 years and above to the number of persons aged 15-64 years.

^c Rates and ranking data extracted from <http://www.worldlifeexpectancy.com/malaysia-population-pyramid>. Rankings are done for approximately 200 countries. All ranking in descending order, eg low digit life expectancy ranking equates longer life expectancy, and a low digit mortality ranking equates to a high mortality rates..

Figure 1: Malaysia's Population Structure, 2000 and 2010

Carta 8: Bilangan penduduk mengikut jantina dan kumpulan umur, Malaysia, 2000 dan 2010
 Chart 8: Number of population by sex and age group, Malaysia, 2000 and 2010



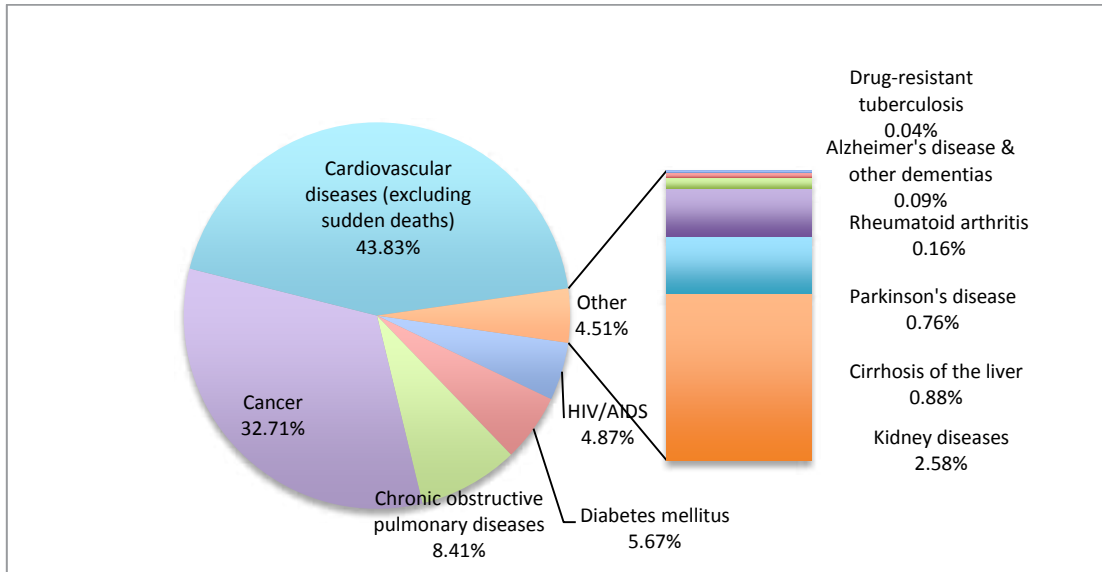
Source: <https://www.statistics.gov.my> ¹⁵

Of concern, Malaysia ranks at an overall 38 out of 80 countries in a 2015 Quality of Death Index developed by the Economist Intelligence Unitⁱ. The index measures Basic End-of-Life Healthcare Environment (rank 42/80); Human Resource (rank 40/80); Affordability of End-of-Life Care (rank=45/80); and Quality of End-of-Life Care (rank =45/80). Community engagement (rank =45/80). This shows that we have a lot of scope for improvement.

Causes of Death in Adults in Need of Palliative Care at End of Life

In Malaysia, our estimate shows that adults comprise of 96.09% of patients needing palliative care at EOL, totalling 54,182 deaths in 2012. A distribution pie chart of causes of death is provided in Figure 3, showing that cardiovascular disease accounts for 43.8%, cancer 32.7%, chronic obstructive airways disease 8.4%, diabetes mellitus 5.7%, HIV/AIDS 4.9% and others 4.5% comprising of kidney diseases, cirrhosis, Parkinson's, Rheumatoid disease, Alzheimer's and drug resistant tuberculosis. These can be largely grouped as chronic disease of lifestyle (CDL) or degenerative diseases or non-communicable diseases (NCDs).

Figure 3: Causes of Death in Adults Needing Palliative Care at EOL

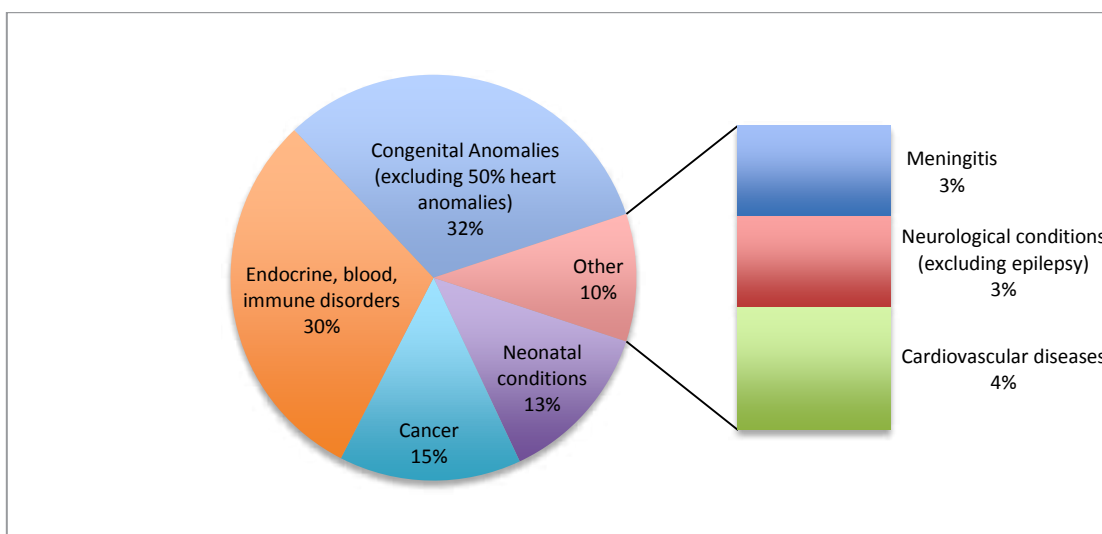


Hospis Malaysia currently receives over 2,000 referrals a year. 90% of these are for patients with cancer only 10% are for patients with other non-cancer diagnosis. Evidence has shown that these non-malignant chronic illnesses have significant symptom burden and will therefore benefit from palliative care, the care approach being similar.

Causes of Death in Children in Need of Palliative Care at End of Life

The number of children in need of palliative care is estimated to be 2,202 or 3.91% of total palliative care needs. The causes of death are substantially different from adults, consisting mainly of congenital anomalies, hereditary disorders, and neonatal conditions and to a lesser degree cancer and infectious diseases. Figure 4 is a pie chart distribution showing the causes of death.

Figure 4: Causes of Death in Children Needing Palliative Care at EOL



As per WHO definition, care for children with life-threatening illness focuses on total care of the child's body, mind and spirit, and starts when the illness is diagnosed. Palliative care for children therefore starts early, and not only focuses on relieving symptoms, but also on actively detracting from conditions that cause distress and curtail enjoyment of living. The different disease profile and approach to care, implies that child specific standards should be reviewed and defined separately¹⁶.

This data shows the burden for palliative care in the country, with an estimate of over 56,000 palliative care cases annually and growing. Approximately two-thirds of this estimate is due to non-communicable diseases, with the remaining third being cancer. This reflects trends in many countries worldwide. Palliative care started with cancer but has widened to encompass all life-threatening illnesses. However in Malaysia, doctors' referrals of patients with non-malignant illnesses for palliative care are still low. Hospis Malaysia sees approximately 90% cancer cases and only 10% non-cancer. In addition, Malaysia ranks poorly in the 2015 Quality of Death Index¹⁷ indicating that there is much to do in improving the end of life care. Whilst the estimate for children requiring palliative care is small, at 3.91% of total estimate, the needs are different, and often more complex, requiring palliative care before treatment, during treatment and post treatment.

Overview of Provider Characteristics

Mapping Palliative Care Services

In the publication ‘Mapping levels of palliative care development: A global update (2013)¹⁸, Lynch T, Connor S, Clark D. published a method to map palliative care development country-by-country based on 4 groups of typology, namely:

“1) No known hospice-palliative care activity, 2) Capacity building activity (but no service yet), 3) Countries with localised provision of hospice- palliative care, and 4) Countries where hospice and palliative care activities are approaching integration with the wider health system.”

In more recent works, this has further been sub-categorised as reflected in [Table 4](#), with Malaysia falling into Group 4a, Preliminary Integration, amongst countries such as Chile, China, Costa Rica, Denmark, Finland, Hungary, Israel, Kenya, Luxemburg, Macau, Malawi, Mongolia, Netherlands, New Zealand, Puerto Ricco.

Table 1: World Palliative Care Association (WPCA) Categorisation of Country Level Palliative Care Development, 2011 (N=234)

Groups	Characteristics
Group 1 No known activity N = 75 (32%)	Although we have been unable to identify any palliative care activity in this group of countries, we acknowledge there may be instances where, despite our best efforts, current work has been unrecognised.
Group 2 Capacity building N = 23 (10%)	In this group of countries, there is evidence of wide-ranging initiatives designed to create the organisational, workforce and policy capacity for hospice-palliative care services to develop, though no service has yet been established. The developmental activities include: attendance at, or organisation of, key conferences; personnel undertaking external training in palliative care; lobbying of policy-makers and ministries of health; and incipient service development.
Group 3a Isolated provision N =74 (31.6%)	This group of countries is characterised by: the development of palliative care activism that is patchy in scope and not well supported; sourcing of funding that is often heavily donor- dependent; limited availability of morphine; and a small number of hospice-palliative care services that are often home-based in nature and relatively limited to the size of the population.
Group 3b Generalised provision	This group of countries is characterised by: the development of palliative care activism in a number of locations with the growth of local support in those areas; multiple sources of funding; the availability of morphine; a number of hospice-palliative care services from a community of providers that are independent of the healthcare system; and the provision of some training and education initiatives by the hospice organisations.

<p>Group 4a Preliminary integration N = 25 (10.7%)</p>	<p>Countries where hospice-palliative care services are at a stage of preliminary integration into mainstream service provision. This group of countries is characterised by: the development of a critical mass of palliative care activism in a number of locations; a variety of palliative care providers and types of services; awareness of palliative care on the part of health professionals and local communities; the availability of morphine and some other strong pain-relieving medicines; limited impact of palliative care upon policy; the provision of a substantial number of training and education initiatives by a range of organisations; and interest in the concept of a national palliative care association.</p>
<p>Group 4b Advanced integration N = 20 (8.6%)</p>	<p>Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision. This group of countries is characterised by: the development of a critical mass of palliative care activism in a wide range of locations; comprehensive provision of all types of palliative care by multiple service providers; broad awareness of palliative care on the part of health professionals, local communities and society in general; unrestricted availability of morphine and all other strong pain-relieving medicines; substantial impact of palliative care upon policy, in particular upon public health policy; the development of recognised education centres; academic links forged with universities; and the existence of a national palliative care association.</p>

Source: Global Atlas of Palliative Care, page 35-40

Similar topography mapping systems have been used to plan and monitor the development of palliative care service standards within a locality or in a country. One such example is looking at the standard of timely access to palliative care. In a UK report titled *Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives, Dec 2012*¹⁹, an observation was made that specialised palliative care can potentially improve both patient and caregiver outcome, and reduce the cost of healthcare by reducing the need for unplanned hospitalisation at the end-of-life. It cited previous research findings, which had shown that unplanned hospitalisation could be secondary to a lack of 24 hour response service, a lack of timely access to advice and medication, and a lack of prompt access to services in the community. Based on this guideline, a mapping exercise was done in London, surveying over 50 PCS (hospitals, hospices and community) and the results published in a report titled *A Review of Specialist Palliative Care provision and access across London, Sept 2015*²⁰. To address the timely access to care standard, services were asked, amongst other data, if they provided face to face visits from 9am-5pm, 7 days a week, and 24 hour phone advice 7 days a week, and the data mapped, monitored and reviewed against staffing levels, demographics, and public health organisations in order to develop, fund and evaluate, appropriate cost-effective services.

Defining Levels for Malaysian Palliative Care Services (PCS)

Using this method, we looked at available data and devised a relevant topography system for a mapping exercise in Malaysia, based on case load, staffing levels, services offered including access to pain medication, and funding sources. The typology as presented in Table 5 is adapted from a Standards Document by the African Palliative Care Association²¹, but takes into account the non-profit organisation (NPO) nature of the services in Malaysia, providing free services and operating within the constraints of their ability to raise funds.

Table 5: Typology used for Mapping Palliative Care Services in Malaysia

Description	Capability requirements	Resource requirements
<p>Voluntary/Social Care level (0) This level represents social care/ home care by volunteers. Nursing or medical services can be provided by volunteer nurses or doctors but these services are not regularly accessible or standardised.</p> <p>It provides supportive care services and relies heavily on referral to a higher level for medical and or palliative care.</p> <p>Current examples of services: Not-for-Profit Societies, Associations, Persatuans'</p>	<p>Supportive care includes:</p> <ul style="list-style-type: none"> • taking & monitoring of vital signs • assisting with mobility & patient transfer • reminding patients or caregivers on medications, but not administer medications • assisting with equipment such as oxygen concentrator, wheel chair, walkers • changing ostomy and catheter bags. • may assist with ADLs, errands, and housekeeping • monitor patients for any changes in their conditions and refer accordingly 	<p>Human resource consists of mainly volunteers. Volunteers can be doctors, nurses or lay volunteers.</p> <p>No full time nursing staff or full time supervising doctor. Clinical supervision is provided at an advisory level.</p> <p>Funding is often from single source, however as it is volunteer based, sustainability is not totally dependent on funding.</p>
<p>Primary/Basic Care level (1) This level represents the minimum package of nursing care provided by staff nurses and nursing aids.</p> <p>It provides both supportive care & basic nursing care and relies on referral to a higher level for medical and</p>	<p>Supportive care (as above) plus basic nursing care including:</p> <ul style="list-style-type: none"> • treat cuts or wounds • give injections • administer medication • change catheters • caregiver training 	<p>Full-time small team of nurses who have undergone orientation course of palliative care</p> <p>Clinical supervision provided by part-time palliative care doctor.</p>

<p>or palliative care. Patient referrals are still small possibly due to limited services or limited awareness of service by healthcare providers.</p> <p>Current examples of service: Not-for-Profit Societies, faith based and service based NGOs</p>	<p>It has on site availability of:</p> <ul style="list-style-type: none"> • WHO step 1 pain management (non-opioid based +/- adjuvant), • Level 2 & level 3 pain management are provided in partnership with higher levels of care. 	<p>Funding - sustainable source of funding is required to cover for staff.</p>
<p>Secondary/Intermediary level (2) This service level represents the minimum package of palliative care and is under the supervision of a full-time doctor and as a consequence provides a wider range of services, regularly servicing a larger patient base.</p> <p>It has developed collaborations with other service provider, including referral doctors.</p> <p>Provides ongoing availability of Step 2 analgesics.</p> <p>Examples of services: Not-for-Profit Societies, faith based and service based NGOs, Centres</p>	<p>Capabilities as levels above.</p> <p>This level provides regular access to medical and nursing care and is able to provide psychosocial support and spiritual input on site.</p> <p>It has ongoing availability of WHO step 2 level analgesics (opioid for mild to moderate pain, +/-non-opioid, +/-adjuvant).</p> <p>It has functionally established and documented referral network.</p>	<p>An interdisciplinary or multi skilled staff team supervised by full-time doctor trained in palliative care.</p> <p>Nurses would have undergone basic palliative course.</p> <p>Funding - sustainable multi-source funding</p>
<p>Tertiary/Specialist level (3) The tertiary service level provides a full range of palliative care service and has a multi-disciplinary team with specialist training. It provides all care elements as levels above plus:</p> <ul style="list-style-type: none"> • Ongoing availability of Step 3 analgesics 	<p>Capabilities as levels above.</p> <p>It has ongoing availability of WHO step 3 level analgesics (opioid for moderate to severe pain, +/-non-opioid, +/-adjuvant).</p>	<p>A multi-disciplinary team with specialist training, skills and experience in palliative care.</p> <p>The staff team includes doctors, specialist nurses, nursing aid,</p>

<ul style="list-style-type: none"> • Certificate or Degree level training in palliative care represented by team. • Availability of palliative radiation and or palliative chemotherapies or clear procedure of referral for access to such treatment. <p>Example of services: specialist palliative care centre, hospital based palliative care units/teams</p>	<p>Receives and manages referrals from level 1 and 2, with clear documentation on the management of such referrals. Can also make referrals back to level 1 & 2 for ongoing joint care.</p> <p>Has formal links with levels 1&2 service providers and provides them with consultant support, training and mentorship.</p> <p>Ongoing availability of well-structured professional supervision for community care providers.</p> <p>There is a well - documented procedure for follow-up on adherence to medications</p>	<p>pharmacist, physiotherapist, social care professionals, etc.</p> <p>A professional team working together with trained community care providers through a well-structured and documented process.</p> <p>Funding - sustainable multi-source funding</p>
--	---	---

The above typology has not taken into account other services including inpatient & outpatient service, day care, equipment loan, or provision of palliative care training programs and or public awareness program which the PCSs may offer.

Background on Community Palliative Care Services in Malaysia

To date we have identified 26 community PCS in Malaysia, all of which are providing free services. To understand these organisations better, we looked at the services as charitable not-for-profit organisations both registered with the Registrar of Societies (ROS), or Registrar of Companies (ROC) and are therefore bound by the regulations of the Societies Act 1966, or Companies Act 1965 respectively.

Simplistically, societies are membership and volunteer based clubs, companies, partnerships or associations of seven or more persons. It generally starts with a group of people defining the objectives of the society, be it to provide common services and or facilities to members, and or specific charitable services and or facilities to the public. A constitution, or rules of operation is drawn to fulfil these

objectives and the society registered before the membership (subscription fee) and or volunteer (usually free) recruitment exercise.

Staff may be employed to administer the society and or provide the services. Funds can come from subscriptions, membership, donations and or grants. Examples are the Persatuan Hospice or Hospice Societies, or Palliative Associations attached to the various state MOH Hospitals. These often have the hospital's doctors and nurses as its members/volunteers, some with no employed staff limiting the scope of the community service. Another example is the Cancer Societies, which were started by doctors to increase public awareness, and prevent and control cancer. As time evolved, the cancer societies have developed an add on community hospice program, which in the case of NCSM Penang, has grown sufficiently for its activities to be transferred to the Penang Hospice Society (2010). Similarly, these societies may be run by volunteers and or full-time administrative and clinical staff.

Not-for-profit services registered under the ROC are not membership based, but they often recruit volunteers to provide support services. In this report we will refer to these entities as NGOs instead of companies, which are either service, or faith based and obtain their funding from donations, fundraising activities and grants. If these public charity entities have substantial financial endowments, they can further apply to be Trust Corporations under the Trust Companies Act 1949 where income can be exempt from the income-tax legislation. Example of a faith base trust company is Pure Lotus Hospice of Compassion, and service base is the Kasih Hospice supported by the Kasih Foundation & Hospis Malaysia.

All non-governmental health services, whether societies or companies are regulated by the Private Healthcare Facilities and Services Act 1998, and as such operational standards should comply with this Act as well as the said Acts above. This report however, will look mainly at the levels of care provided.

Mapping Levels of Malaysian Palliative Care Development

Data on PCS were obtained from three sources, namely:

1. The program booklet of the 9th *Malaysian Hospice Congress (2010)* compiled by Malaysian Hospice Council²² provided census and service data for Y2009 by participating services (n=15).
2. More recent information on community PCS were obtained from a questionnaire survey conducted by Hospis Malaysia. A total of 25 community services were identified, 17 of these services responded to the survey.
3. A web search provided additional information on these services.

The information on each service was tabulated and characteristics reviewed to assign a level of development as described in the typology in [Table 5](#). Due to the limited data collected, [Table 6](#) lists the number of PCS's according to developmental level. These services are mapped using batchgeo¹, an online application, to give an idea of the extent and distribution of services.

¹ <http://batchgeo.com>

Table 6: The number of PCS in Malaysia based on Levels of Development (n=26)

Levels of Development	Number of PCS in Malaysia (total n=26)
Level 0 Voluntary/Social Care level	7
Level 1 Primary/ Basic Care level Minimum Package of Nursing Care	4
Level 2 Secondary/ Intermediary level Minimum Package of Palliative Care	4
Level 3 (n=4) Tertiary/Specialist level Multidisciplinary Care	5
No Information (n=6)	6

These classifications are made with limited data, and we accept that this may not be accurate. In particular, we are unable to fully ascertain caseloads, capability on internal processes and drug prescription/dispensing ability, and resource levels. We have tried to categorise the level and distribution of PCSs and what it suggests is that only KL, Penang and Sandakan have tertiary level services.

There are 18 services in West Malaysia as represented by the map in [Figure 5](#) with two small clusters of services in Penang (3 services), and Kuala Lumpur/Selangor (5 services). As per [Table 7](#), these states/Federal Territory have higher population density, enabling better or more efficient reach by a community hospice service, and are also where the tertiary services are located. All other state services are currently at Level 1, primary or basic level with no full-time supervision by a doctor, and Level 2, Secondary/Intermediary level with supervision by a full-time doctor.

Figure 5: Mapped Location of PCS in West Malaysia (n=18) and East Malaysia (n=8)

In East Malaysia, there are eight services located at major towns. Due to the large land mass, it makes it even more important for healthcare providers to be trained in palliative care.

Figure 5: Mapped Location of PCS in West Malaysia (n=18) and East Malaysia (n=8)



WEST MALAYSIA

Johor	
Johor Bahru	2
Kedah	
Alor Setar	1
Kelantan	
Kota Bharu	1
Terengganu	
Kuala Terengganu	1
Malacca	
Malacca	1
Negeri Sembilan	
Seremban	1

Pahang	
Kuantan	1
Penang	
Georgetown	3
Perak	
Ipoh	1
Taiping	1
Selangor	
Klang	1
Petaling Jaya	3
Kuala Lumpur	
Klang Valley	1

EAST MALAYSIA

Sabah	
Kota Kinabalu	2
Keningau	1
Sandakan	1
Tawau	1
Sarawak	
Kuching	2
Miri	1

Table 7: Hospices, Population, Population Density and Estimated Number of Patients Requiring Palliative Care in Each State / FT in Malaysia

State/ Federal Territory [16]	Population (Y2010)	Population density (ppl/km2) (Y2010)	Estimated no. of new patients requiring PC for Y2012 (n=56,384)	Estimated no. of patients referred to community hospices Y2009
FT Kuala Lumpur (FTKL)	1,627,172	6,891	3,315	2,392
Selangor	5,411,324	670	11,023	Included in FTKL estimate
FT Putrajaya	67,964	1,400	138	Included in FTKL estimate
FT Labuan	86,908	950	177	0
Johor	3,348,283	174	6,821	288
Kedah	1,890,098	199	3,850	151
Kelantan	1,459,994	97	2,974	128
Malacca	788,706	470	1,607	266
Negeri Sembilan	997,071	150	2,031	112
Pahang	1,443,365	40	2,940	N/A
Penang	1,520,143	1,500	3,097	639
Perak	2,258,428	110	4,600	261
Perlis	227,025	280	462	0
Sabah	3,117,405	42	6,350	370
Sarawak	2,420,009	19	4,930	91
Terengganu	1,015,776	69	2,069	N/A
TOTAL			56,384	4,698

Source:

https://en.wikipedia.org/wiki/Demographics_of_Malaysia#Population_distribution_by_states_and_territories;

https://en.wikipedia.org/wiki/List_of_Malaysian_states_by_GDP

9th Malaysian Hospice Congress, Communication for Better Care 7th-9th May 2010

In column 4 above, as an indication of service needs in each state/FT, we provide a rough estimate of the annual number of new patients requiring palliative care services by using population ratios multiplied by 56,384 patients which is the estimated total number of patients requiring palliative care (refer to Table 1)

We then attempted to demonstrate the potential gap between need and capacity by estimating during a similar period, the number of patients receiving palliative care in the community (as a guide of existing capacity, as no data was available for patients covered by hospital palliative care units) - column 5. It is found that existing capacity met 8.3% of the need.

Challenges and Barriers to Community Palliative Care Service Development

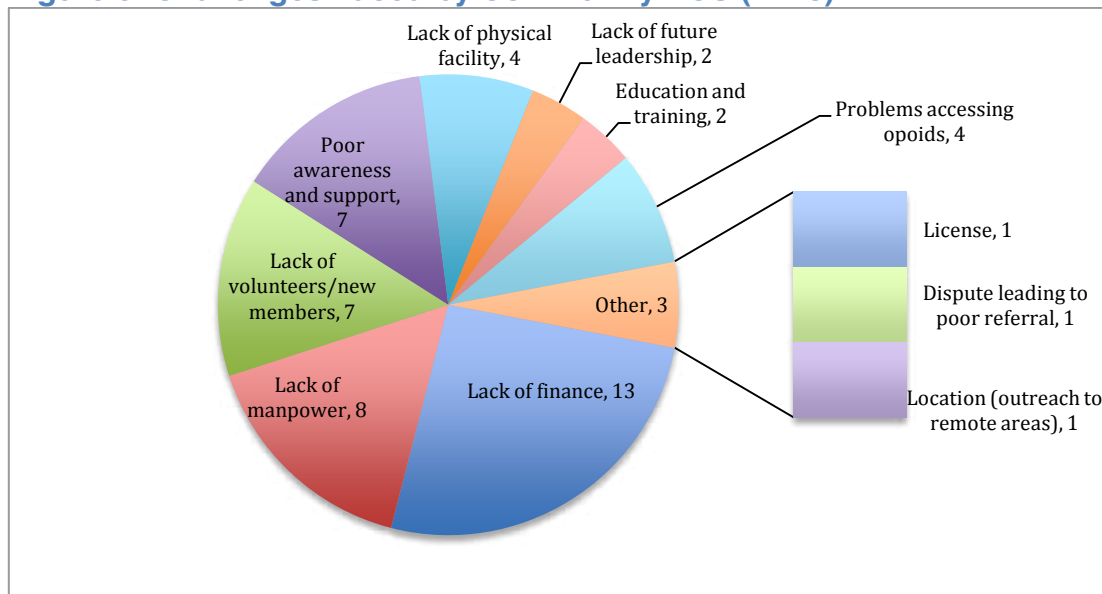
In defining the typology for PCS, we have attempted to use predefined levels of service provision. This is to assess the current level of provision and suggest to highlight some standards and to define developmental goals for community PCS. However, there are significant barriers to establishing a community service including availability of resources, awareness of stakeholders, supporting policies, and organisation structures or systems that enables the PCS to grow. It is not in the scope of this report to explore these barriers in detail; however we highlight some of the issues identified by the PCS in the data collected.

Out of the 26 PCS, we have obtained data from 18 of these services on challenges they face in running the community service. These challenges are reflected in [Figure 6](#) with the top three main issues being a lack of financial resources (72%), a lack of staff and or volunteer and members (72%), and the poor awareness and support for the PCS (39%). Four of the services indicated problems accessing opioids, and another five stated that a lack of physical facility (21%) as a challenge.

In addition PCS are concerned as follows:

- PCS society is concerned regarding the *“Lack of dynamic dedicated leadership in the future”*;
- PCS expressed disappointment regarding differing views and priorities for palliative care service development between government and non-government organisations;
- An inpatient PCS has issues regarding the slow approval of licensing;
- PCS society find the *“Perpetual need to recruit, train and sustain staff and volunteers”* a challenge.
- Dispute on case management causing the lack of referral, and in turn causing the program to stagnate.

Figure 6: Challenges Faced by Community PCS (n=18)



PCS often raise funds from multiple sources, from memberships & subscriptions, donations (personal & corporate), fund-raising activities, grants (government & private) and in one case, from the rental of its premise to a hospice shop.

13 PCS's find raising funds a challenge, with concerns ranging from *"long term sustainability, especially financial"*, to *"no budget to make payment/ to hire"*. Three of the services, are actively looking to fill a staff position for fund-raising.

Some feedback on the lack of manpower include, *"difficulty to employ qualified doc & nurses"*, challenge to *"retain nurse and maintain high standard of care"*, *"lack qualified doc, nurses, volunteers, counsellors"*, and *"difficult to match salaries offered across the causeway and lack of people with the right competency and aptitude"*.

Some of the PCS have indicated a difficulty in recruiting volunteers *"voluntary work is not as attractive to most people"*, and *"no interest in voluntary work"*. For societies attached to MOH hospitals, feedbacks on volunteers include *"infrequent home visits due to work overload, and lack of funding depending on MOH"*.

Concerns over poor awareness of palliative care are captured by the following feedbacks: *"There is a general lack of awareness on palliative care and its benefits even among the specialist doctors in many regional hospitals. As a result, patients are not referred to us or are only referred to us on their very last days – thus depriving these patients from deriving the maximum benefit out of palliative care"*, *"lack of environment of support from main stream medicine"*, and *"public awareness & education as well as among professionals regarding palliative services & patients' right to such care"*.

Five services indicated the lack of physical facility as a barrier to growth, and are *“seeking fund to start day care & resource centre”, “buy O2 concentrator & other equipment”, “establish OPC, counselling centre, medical store, training centre”, “need own office/building, vehicle for home visit”, and “lack of day care centre”.*

When asked “Do you have problems accessing opioids and other controlled medicines?” four of the services said yes including an inpatient facility, whilst twelve services said no, *“our patients are hospital based. All medication is given by hospital”, “so far not much problem”; “most of our patients manage to have access to opioids via government hospitals.”*

There are major limitations to this attempt to map the current status of palliative care provision in the survey. However it does show that the distribution of services is limited to urban areas and in many cases depends on volunteers rather than trained health care professionals. A more detailed study of the type of care delivered would help to give a baseline from which to plan. Resources have historically always been limited and are unlikely to change without more structure and funding. This makes it even more critical to define clear developmental goals, form effective supporting network of services and where possible share resources. The end goal must be to facilitate the development of palliative care and where possible assist in the implementation of standards.

Public Awareness Survey Supports a Public Health Model for Palliative Care

We present the results of a recent community survey conducted by Hospis Malaysia in 2015 to ascertain the community’s expectations and perceptions of palliative care services. The survey was adapted from “The Way Forward Survey Report, Dec 2013” a survey by the Canadian Hospice Palliative Care Association. Hospis Malaysia contracted a market research company to conduct face-to-face interviews with randomly selected people in cities and sub-urban areas in Klang Valley, Penang, Johor & Pahang representing states in the north, central, south and the east of Peninsula Malaysia. A total of 600 completed interviews were done and a separate paper presenting the full results is available, however in this report we present an abridged version looking at respondents:

- A. Health status and health seeking behaviour,
- B. Thoughts and preference regarding end-of-life (EOL)
- C. Knowledge, attitudes and expectation towards palliative care

The objective of which is to identify from the community, their care needs and to have a better insight of their awareness, perception and expectations in order to provide relevant data for the planning of services and public awareness campaign.

Results of Public Awareness Survey

A summary of the demographic composition of respondents in our survey is presented in [Table 8: Demographic Profile of Participants \(n=600\)](#). The respondents’ demography corresponds proportionally to the national ethnic, age and state distribution. In addition, the majority of respondents are/were married (63%), employed (75%), and have completed secondary education and or higher education (93%).

		Number	Percentage
Ethnicity	Chinese	195	32.5%
	Malay	344	57.3%
	Indian	61	10.2%
Age	21-34yo	271	45.2%
	34-55yo	269	44.8%
	>56yo	60	10.0%
Gender	Male	300	50.0%
	Female	300	50.0%
State	Klang Valley	319	53.2%
	Penang	73	12.2%
	Johor	142	23.7%
	Pahang	66	11.0%
Location	City	495	82.5%
	Sub-urban	105	17.5%

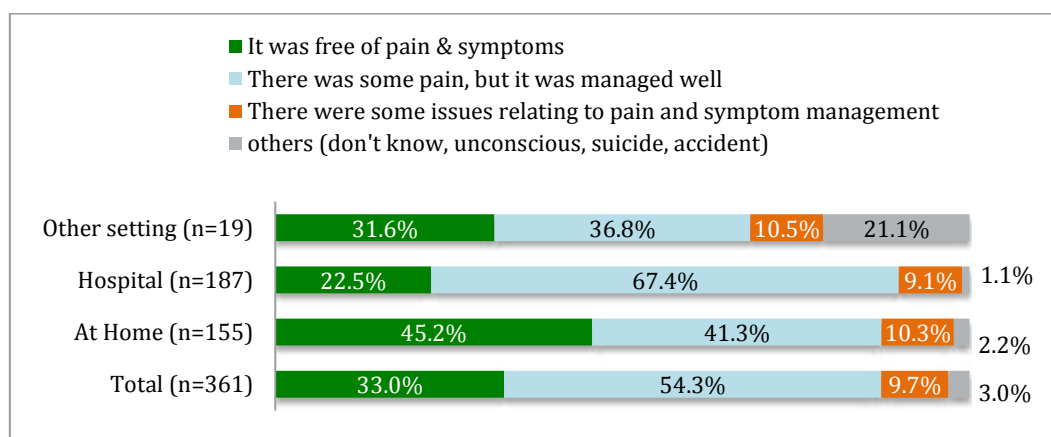
Table 8: Demographic Profile of Participants (n=600)

A. Health Status and Health Care Seeking Behaviour

We looked at the health status of families and their health seeking behaviour and found that a minority of respondents have a regular family physician (31.8%). The survey also showed that chronic illnesses is common in families (53%), and is associated with a high incidence of hospitalisation, with 1 in 4 respondents with chronic illness, and 3 in 4 family members, having been hospitalised in the last year. In addition for respondents who are/had cared for a family member with a chronic condition, a large majority (92.6%) had given up employment. For those who are not currently involved in caring for a family member, 73.5% expects to play a role in the care of one or more of their family members in future.

Of our 600 respondents, 361 respondents (60%) had a family death in the past 10 years. The majority of these deaths occurred in hospital (51.9%) and at home (43.1%) with the remaining deaths (5%) occurring at an accident scene or on the way to hospital. Of these a third (33%) of respondents felt that their family member's death was free of pain and symptoms, another 54.3% felt that there was some pain but it was well managed, whilst 1 in 10 felt that there were some issues relating to pain and symptom management. [Figure 7](#) compares end-of-life experiences at home and in hospital. A higher percentage of home deaths (45.2%) are free of pain & symptoms compared to 22.5% of hospital deaths. Respondents were more likely to say that their family member experienced some pain but it was well managed if the death occurred in hospital. This finding could be due to their family member suffering from pain at the EOL, and going to hospital to manage the pain. Issues relating to pain and symptom control were experienced at similar levels in both hospital (9.1%) and home (10.3%).

Figure 7: Thinking of the family member who passed away, which of the following best describes their end-of-life experience? (n=360)

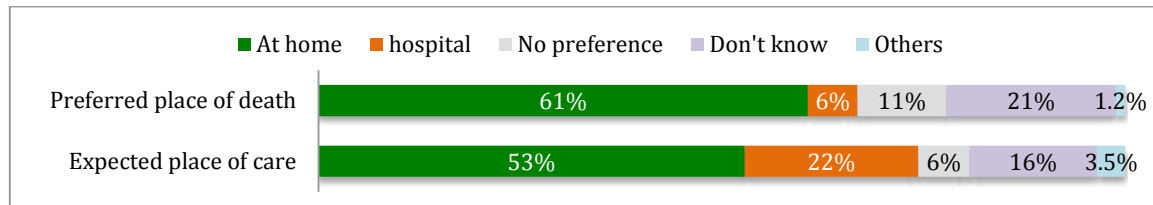


B. Thoughts and Preference Regarding End-of-Life

More than half (56%) of respondents have thought about EOL. These thoughts are more likely to occur in Malays (66.7%) & Indians (60.2%) and least likely in Chinese (42.1%); it more likely to occur with increasing age >55yo (66.7%), if the respondents are in poor health (66.7%) and if both respondents and their family members have a chronic illness (72.7%).

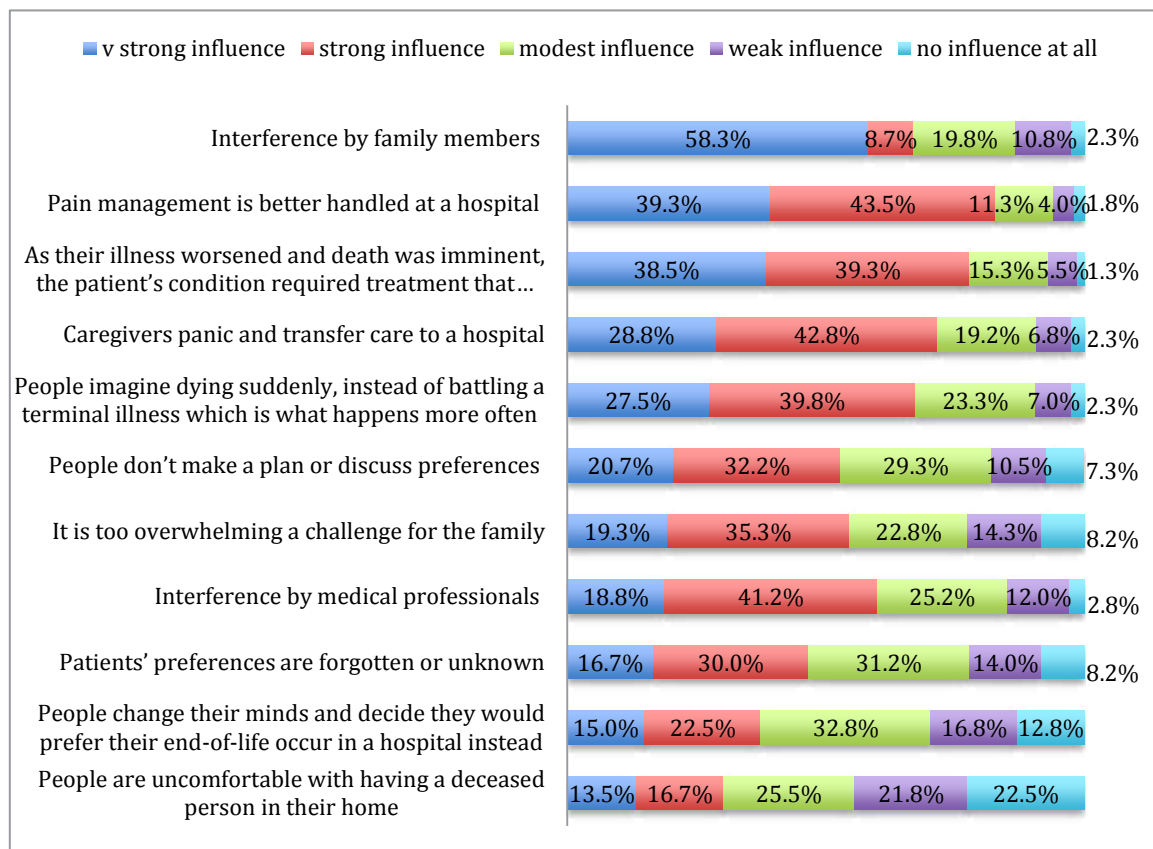
For EOL, the majority of our respondents **prefer to receive the bulk of care at home (53%) and prefer to die at home (61%)** (Figure 8), with a minority opting to receive the bulk of their care in hospital (22%) and even smaller minority opted to die in hospital (6%). In the figure, others included Mecca, nursing homes, and other health care facilities.

Figure 8: Respondent's preferred place of death and where they expect to receive the bulk of their care (n=600)



To understand why more deaths occurred in hospital compared to the preferred home death, respondents were asked to rate a list of 11 reasons which may influence why people end up dying at hospital. Figure 9 below shows that the majority of respondents feel that interference by family is a very strong influence, pain is better managed at a hospital, and as death is imminent the patient required treatment that could only be provided in hospital.

Figure 9: Influencing Factors of why People Die at Hospital despite a preference to die at home

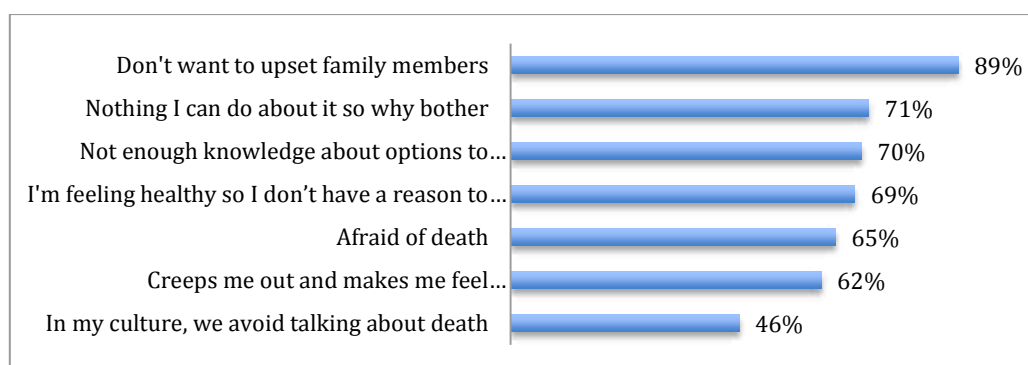


Preference to Die at Home

Our cohort were asked if they thought it was important to talk to someone about EOL preference, and if they have ever talked to a family member, doctor, lawyer, friend, or financial advisor about their end-of-life care preferences (Figure 10). Two thirds (65.7%) of respondents said it was important to talk to someone whereas a third (35%) have actually discussed their EOL preferences, mainly to their families (31%) and or friends (9%), doctor (3%), financial advisors (1%) and lawyers (0.3%). Data indicates that as respondents become older, they are more likely to think it is important to talk to someone, and to proceed to talk to someone regarding their EOL preferences.

Overall the three main reasons why our respondents think people might be reluctant to discuss EOL care is, *“not to upset family members”*, *“nothing can be done about it so why bother”* and *“not enough knowledge about options to discuss”*. Other reasons respondents gave as relevant include death is a norm (16), refuse to talk about it during healthy state (2), *‘pantang’/bad omen to talk about death* (3), uncomfortable discussing about death (2), not interested to talk about death (2), oblivious about death (6), do not know who to talk with about death (1).

Figure 10: Reasons why respondents think people might be reluctant to discuss EOL care



C. Knowledge, Attitudes and Expectations towards Palliative Care

In this section, we explored the level of awareness of palliative hospice care amongst Malaysians. Their expectation on the type of services offered, where these services are offered and who they are offered for. We asked about their previous experience with palliative care, where they would source for information if needed, and if they supported this type of services.

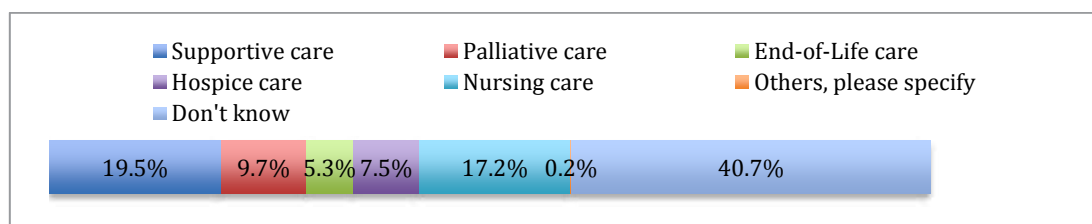
We asked respondents if they are aware of:

“A type of health care to relieve the suffering and improve the quality of life for patients and their families living with or dying from a chronic illness.”

One in four (24.7%) of the respondents said yes. However, when given a multiple choice list of care services and asked what term they would associate with this type of service **only 2 out of 10 Malaysians (17.2%) correctly identified it as hospice care (7.5%) or palliative care (9.7%).**

Figure 11 suggests that the majority of the public is not aware or maybe confused regarding the term palliative/hospice care.

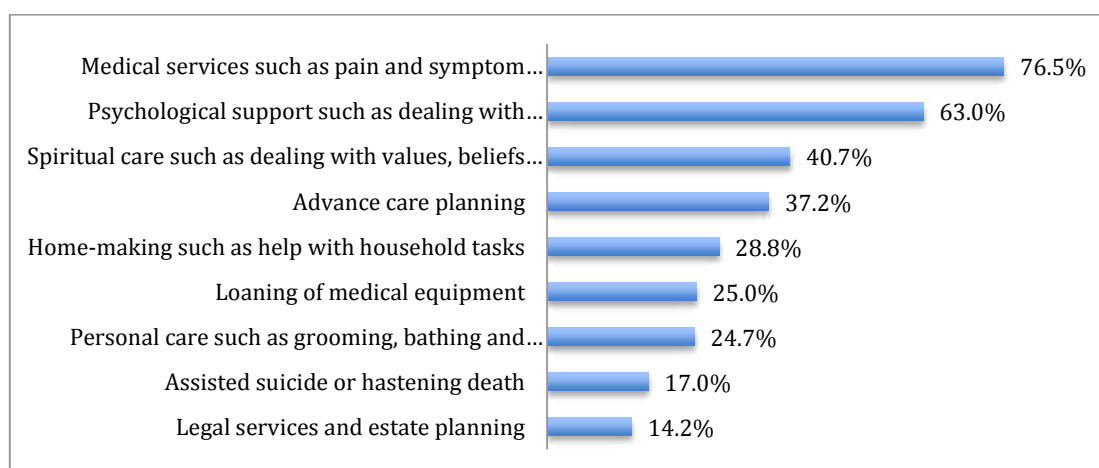
Figure 11: What term would you associate with this type of care? (n=600)



Respondents were then given a list of locations and asked if palliative care is offered there. Half of the respondents (53.1%) think that these services are offered in government hospital, 40.3% in private hospital, 26.5% in nursing home and 25.5% at home. A few respondents specified other facilities including community centre, residential area, sub-urban area, religious institution, charity / societal club, mobile hospital and hospice.

Similarly, respondents were given a checklist of services and asked to identify services included in palliative care. Figure 12 represents the percentage of respondents who think that the specified service is part of palliative care. Leading the list are medical services (77%), psychological support (63%), spiritual care (41%) and advance care planning (37%) which are services currently offered by some of the hospice palliative care centres in Malaysia. A smaller percentage of respondents included home-making services (29%), personal care (25%) and loaning of medical equipment (25%). Fewer suggested legal services and estate planning (14%) and assisted suicide/hastening death (17%) which is not part of palliative care.

Figure 12: To the best of your knowledge, does palliative care include any of the following? (n=600)



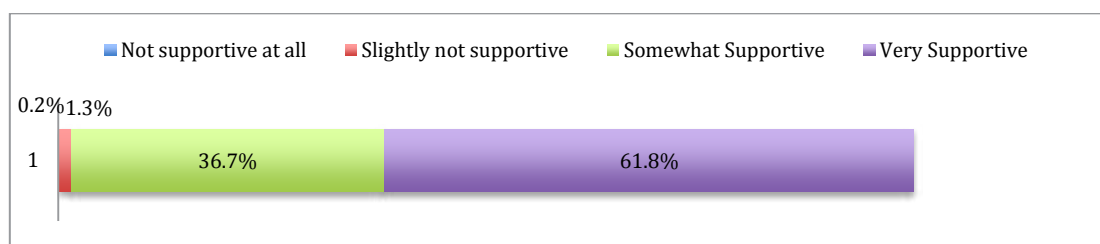
The majority of respondents (63%) indicated that palliative care should be made available to all patients at the EOL regardless of illness. Only (13%) of patients said that it should be for only patients dying of a life threatening disease like cancer or HIV/AIDS. Whereas a quarter of respondents do not know who these services should be made available for.

When respondents were asked where they would source for information on palliative care services, the majority (70%) indicated hospital, 30-40% will surf the web for information, whereas 20-30% will engage other community health services such as family physician, health centres and community nurses. One in five will communicate with friends and family members, whilst a smaller percentage will consult a nursing home (14%) or pharmacist (7%). Many of these respondents will have multiple sources. Other sources of information include health care organisations, roadshows/events, community centres and traditional health care providers.

We provided the definition below and asked respondents if they are not supportive at all, slightly not supportive, somewhat supportive and very supportive of the approach. (Figure 13)

“Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through pain and symptom management, including physical, psychosocial and spiritual. Care in the last days and weeks of life are just one component of palliative care. Overall, what is your attitude towards this type of approach to end-of-life care?”

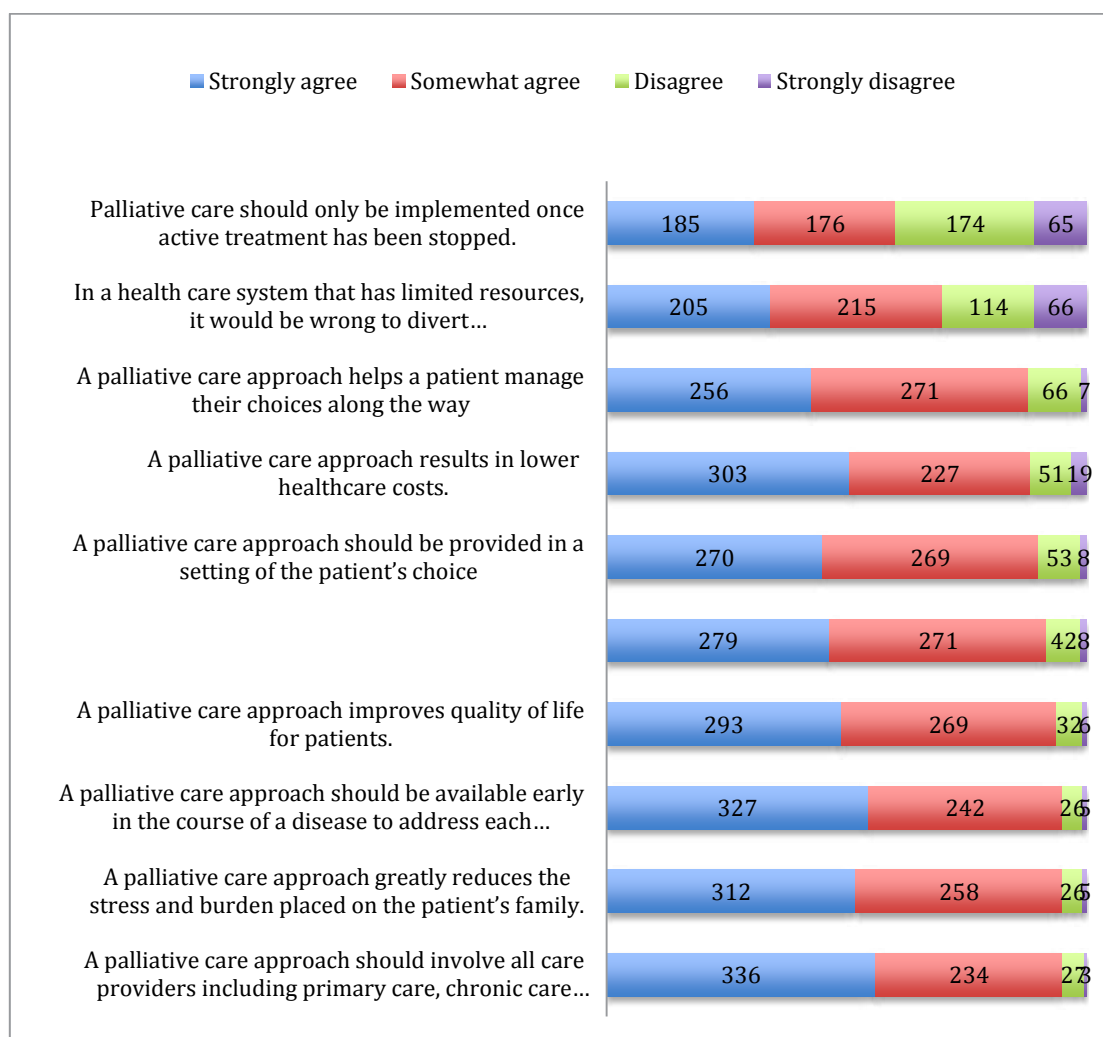
Figure 13: Support for palliative care approach



Support is almost unanimous with 98.5% supportive, 61.8% of which are very supportive and 36.7% being somewhat supportive. 8 respondents are slightly not supportive and only one was not supportive at all.

When given a set of statements for respondents to rate in agreement or disagreement, respondents are generally very supportive of palliative care approach Figure 14.

Figure 14: Agreement with Statement about Palliative Care



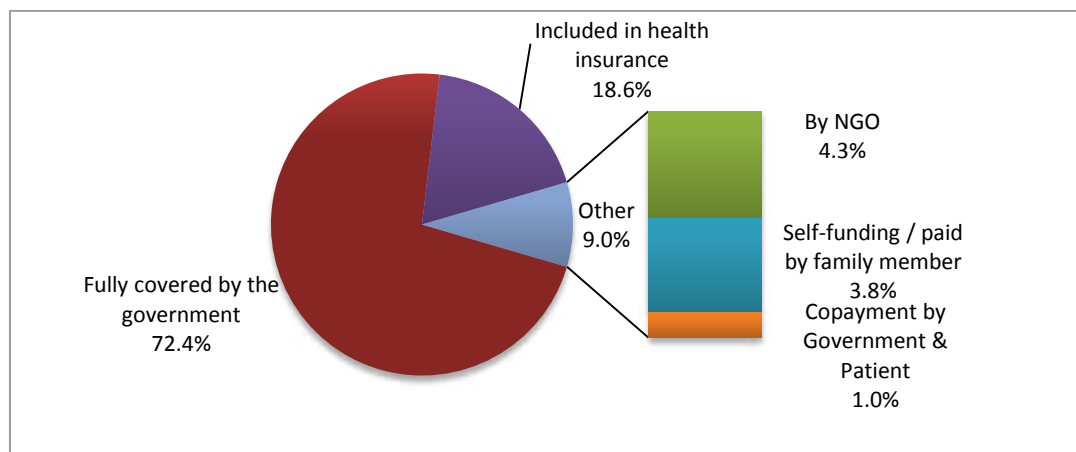
They either strongly agree or somewhat agree with the following statements:

- It should involve all care providers including primary care, chronic care and long-term care practitioners (95%);
- Greatly reduces the stress and burden placed on the patient's family (95%);
- It should be available early in the course of a disease to address each patient's needs (94.8%);
- It improves quality of life for patients (93.7%);
- It could and should be integrated into care for all people with chronic, life-limiting conditions (91.7%);
- It should be provided in a setting of the patient's choice (89.8%);
- Results in lower healthcare costs (88.3%);
- Helps a patient manage their choices along the way (87.8%);
- In a health care system that has limited resources, it would be wrong to divert more money to end-of-life (70%);
- Palliative care should only be implemented once active treatment has been stopped (60.2%).

Though still a majority, a smaller majority are concerned about resources and feel that it would be wrong to divert more money to EOL and that it should only be implemented only once active treatment is stopped.

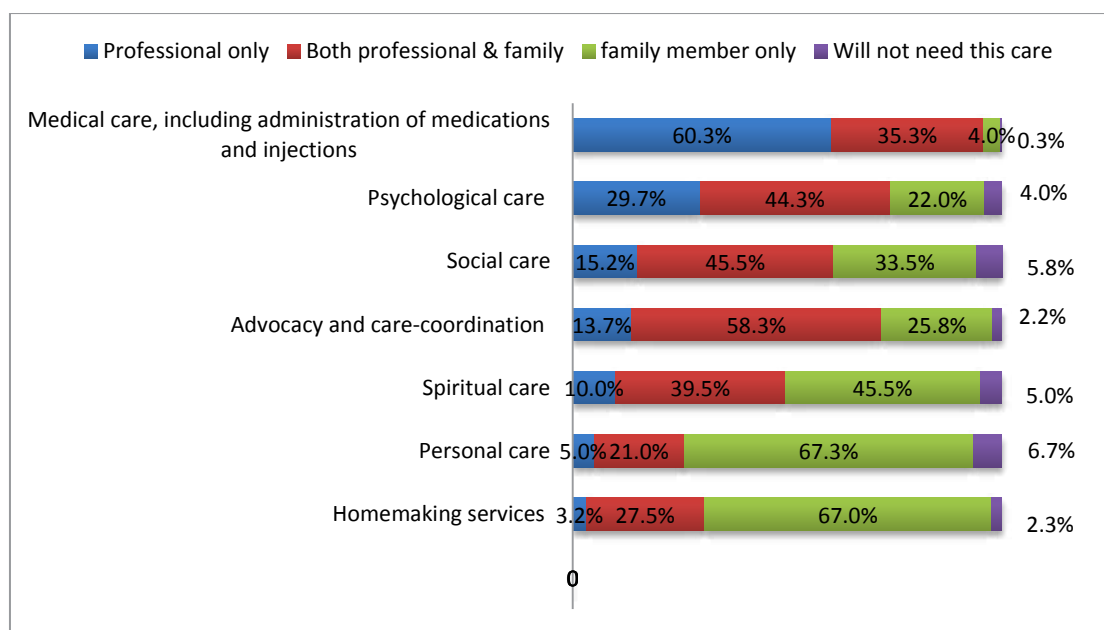
Respondents were asked who should be paying for palliative care (Figure 15). The majority 70.7% indicated government; and 18.3% said that it should be included in health insurance. A smaller percentage indicated NGO (4.2%), self-funding (3.7%), and co-funding between government & patient (1%). One respondent mentioned Baitumal/Zakat.

Figure 15: In your opinion, who should be paying for palliative care?



Several care aspects were listed and respondents were asked “In thinking about your final months of life, do you expect this kind of care will be provided by a professional, by a family member, by both a professional and a family member, or do you expect you will not need this kind of care?”

Figure 16: Expectations from Care Providers for Palliative Care



As per [Figure 16](#) the majority of respondents expect health care professionals to be involved in providing medical (95.6%) and psychological care (74%). In contrast, 80-90% of respondents expect family members to be involved in social care, care-coordination, spiritual care, personal care and home-making services. Only a small percentage of respondents said they will not need the various forms of care.

The results from this public awareness survey show that chronic illness is common in families, and is associated with hospitalisation towards the end-of-life. Whilst the vast majority of Malaysians preferred to receive the majority of care, and to die at home, hospital deaths had accounted for slightly more than half the deaths of their family members. The survey also indicated that the majority of Malaysian's feel that it is important to discuss end-of-life options with their families. However, there are barriers, mostly sociocultural, attributed to the lack of awareness and information on palliative care. For instance, we found that the Indian community feels that it is important to talk to family members about EOL, but that many of them do not for fear of upsetting family members. Others feel that there is not enough knowledge, and that since nothing can be done about it they don't see why they should bother. Palliative care can address this, however awareness and access to service is currently limited.

Our survey shows that over 80 percent of the public are not aware or may be confused regarding the term palliative/hospice care. But, when informed regarding it, they are almost unanimously supportive of it, with the majority indicating that it should be made available to all patients at the end-of-life, regardless of illness. The scope for care for the dying is wide and ranges from medical, psychological, social, care coordination, personal to homemaking services. Generally, respondents expect healthcare professionals to be involved in medical and psychosocial care, and family to be involved in the day-to-day care.

As expected the majority of respondents will source for information on palliative care through their primary doctors and or expect palliative care services to be provided in government and private hospitals, as a follow on from the management of their chronic illness. As a service in transition, it will be practical to design and implement a palliative awareness and evaluation program for doctors in primary care and hospitals, aimed at improving quality of life for patients and care givers at the EOL. Particular focus should go towards identification of patients requiring palliative care; the use of available/standard diagnostic tools; the importance of treatment options, the order of treatment and associated risks/benefits; and working as an integrated team.

Death and dying is a normal part of living and palliative care aims at helping patients die well, providing a sense of dignity to the dying. Clearly, our survey results demonstrate that there is a community role for palliative care. However, this requires a top-down approach, driving policies, funding, standards and guidelines, training and education, and a bottom-up approach with communities accepting palliation as a care option and participating with caring for their love ones at home.

Discussion

The needs assessment data shows that the emphasis of palliative care on cancer needs to shift and services need to develop to include patients with other life threatening illnesses such as renal failure, heart failure, COPD and certain neurological diseases. An estimated 56,000 patients will require palliative care in a year and this number will grow in coming years as the population ages. Much of this care can be provided by patients' primary medical teams, but the health care professionals caring for such patients need palliative care education. Palliative care is not yet included in all medical undergraduate programs and is not addressed in further specialist training.

The numbers requiring palliative cares are supported by the data from the public awareness survey this showed that 53% of respondents had someone in their household with a chronic illness. The public awareness survey, a 600 representative population study, also showed that people want to talk about end of life care, and 56% have thought of end of life issues. The majority want their care to be in the community and would like to die at home, however most deaths had not occurred at home. While this data relies on recall, it does support the need to involve the public in discussions on palliative care strategies. The goal of palliative care is to improve quality of life. Where and how they access care, can and often does impact on their quality of life and influence their decision making with regard to medical treatment.

The mapping of services available in the community shows that the distribution of services is uneven with most services concentrated in the major cities and of variable standards. And less than 10% of existing needs are being met. It is important that we define the level of service and standard of care required to deliver palliative care. Palliative care services can then strive to develop to provide evidenced based professional palliative care. The challenges are finding motivated doctors and nurses to work in these areas.

Implementation requires a structure with agreed guidelines and standards to inform further development of services. A National Strategy for palliative care, which works across primary, secondary and tertiary care, needs to be developed with input from all the major stakeholders such as Ministry of Health, private hospitals, community palliative care services, patients and their informal carers. It should address issues of implementation, education and training and opioid availability, as described in the PHS.

Another factor in delivering palliative care is opioid availability. Feedback from other community palliative care providers' show that opioids are accessible however data from the International Narcotics Board (INCB) shows that consumption in the country as a whole is low. The factors influencing consumption of opioids are not part of the scope of this report but need to be addressed as part of the national strategy.

Delivering high quality palliative care is not just the responsibility of palliative care specialists but requires all health care professionals caring for patients with life threatening illness to be able to provide good symptom control, psychosocial, and spiritual support and to be able to discuss and support decision making around patients' and families' goals of care. This kind of care needs to be available at every level of health care with emphasis on care in the community. Focusing on education will also help fill some of the gaps in provision of care in the community.

Education and training therefore needs to be provided at undergraduate and specialty training level for all health care professionals. While developing palliative care as a specialty is important, palliative care training should also be included in other specialty training. Making palliative care a mandatory part of these courses will mean more patients getting access to quality palliative care.

WHO in its policy document on Public Health Model for the development of palliative care, focused on policy, education, drug availability and implementation. In the same way, Malaysia needs a cohesive national palliative care strategy to address these needs, and develop policies, and allocate adequate funding and resources to enable the PHM to be planned and implemented throughout the care spectrum, as reiterated during the World Health Assembly of 2014.

The transition of services from inpatient to community-based implies a change in delivery structures, requiring a more interdisciplinary approach with collaboration between front line palliative care nurses and their supervising doctor and or patient's primary consultants. There is a need to support the information and skill base of these front liners and strengthen the institutional framework in which palliative care decisions are made, providing reassurance to patients and their families. In addition, quality standards and logistics need to be established to ensure effectiveness and accessibility of the service.

After 25 years of community palliative care services run by NGO's progress has been slow and needs are rapidly growing, as palliative care evolves and our population ages. If we are to have comprehensive community palliative care services available, NGOs cannot do this alone. This data should serve as a discussion point for all stakeholders to drive debate around the standards and model of palliative care for Malaysia.

References

1. El-Jawahri A, Greer JA, Temel JS. *Does Palliative Care improve outcomes for patients with incurable illness? A review of the evidence.* *Journal of Supportive Oncology* 2011 May-Jun;9(3):87-94
2. Higginson IJ, Evans CJ. *What is the evidence that palliative care teams improve outcomes for cancer patients and their families?* *Cancer J.* 2010 Sep-Oct;16(5):423-35
3. Temel J S, Greer JA, Muzikansky A, et al *Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer* *N Engl J Med* 2010;363:733-42
4. *Strengthening of palliative care as a component of comprehensive care throughout the life course*; Sixty-Seventh World Health Assembly; 24 May 2014; WHA67.19, Agenda item 15.5
5. *The Public Health Strategy for Palliative Care*; Jan Stjernswärd, MD, PhD, FRCP (Edin), Kathleen M. Foley, MD, and Frank D. Ferris, MD; *Journal of Pain and Symptom Management* Vol. 33 No. 5 May 2007; Page 486-493
6. *Palliative Care in Norway: A National Public Health Model*; Stein Kaasa, MD, PhD, Marit S. Jordhøy, MD, PhD, and Dagny Faksvåg Haugen, MD, PhD; *Journal of Pain and Symptom Management* Vol. 33 No. 5 May 2007; Page 599-604
7. Christopher Edward Falls MA MBA (2008) *Palliative Healthcare: Cost Reduction and Quality Enhancement Using End-of-Life Survey Methodology*, *Journal of Gerontological Social Work*, 51:1-2, 53-76. <http://dx.doi.org/10.1080/01634370801967554>
8. *Palliative Care Services Operational Policy*; *Medical Development Division, Ministry of Health*; MOH/P/PAK/203.10(BP); 2010 Page 35
9. http://www.who.int/nmh/Global_Atlas_of_Palliative_Care.pdf
10. <http://www.healthdata.org/research-article/estimating-population-cause-specific-mortality-fractions-hospital-mortality>
11. Van den Beuken-van Everdingen MH et.al. (2007). *Prevalence of pain in patients with cancer: a systematic review of the past 40 years.* *Ann Oncology*, 18(9), 1437-49
12. <http://www.jpn.gov.my/en/perkhidmatan/kaedah-2-pendaftaran-melalui-waris-si-mati-atau-pemaklum-kematian/>
13. *WHO mortality data*
14. Health Informatics Centre, Ministry of Health, (2014). *Health Indicators 2014.* able 2.8. : Deaths (Number and Rate*) by Specific Age Groups, Malaysia, 2011 – 2012. Page 58
15. <https://www.statistics.gov.my>
16. American Academy of Pediatrics, Committee on Bioethics and Committee on Hospital Care (2000), *PEDIATRICS* Vol. 106 No. 2 Aug 2000, page 351-357

References

17. *The 2015 Quality of Death Index. Ranking end-of-life care across the world*; Economist Intelligence Unit 2015
18. *Mapping levels of palliative care development: A global update*, Lynch T, Connor S, Clark D. (2013). *Journal of Pain & Symptom Management*; 45(6):1094-1106
19. *Commissioning Guidance for Specialist Palliative Care: Helping to deliver commissioning objectives*. Association for Palliative Medicine of Great Britain and Ireland, Consultant Nurse in Palliative Care Reference Group, Marie Curie Cancer Care, National Council for Palliative Care, Palliative Care Section of the Royal Society of Medicine. Dec 2015
20. London Cancer Alliance, PallE8, Marie Curie. *A review of Specialist Palliative Care provision and access across London , Mapping the capital*, Sept 2015
21. African Palliative Care Association, *Standards for Providing Quality Palliative Care Across Africa, 2011*, page 18-19 Service levels upon which the standards are based
22. 9th Malaysian Hospice Congress, *Communication for Better Care 7th-9th May 2010*
23. <http://www.painpolicy.wisc.edu/global> INCB opioid consumption data.

About Hospis Malaysia

Hospis Malaysia is a leading organisation for palliative care in Malaysia. In line with its increasing focus on advocacy for greater accessibility to palliative care in the country, it continues to strengthen its lead position in education and training in palliative care while offering the highest possible quality of palliative care to patients in the Klang Valley. The organisation is committed to advancing palliative care programs and research with the aim of ensuring that palliative care, which is already part of the WHO definition of 'Universal Health Care', becomes fully integrated into the country's health care system.

Photo Credit: **SC Shekar** | Design by: **SMALLTIMER**

supporting



palliativecare.my