

Palliative care in Malaysia: the need to do much more

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INTRODUCTION

The World Health Organization (WHO) defines palliative care (PC) as an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.¹ Hospice care focuses on the palliation of pain and symptoms of terminally ill patients, in addition to attending to emotional and spiritual needs till the end of life. Care is extended to provide emotional support to both client and family, apart from assisting decision-making about needed treatments.² In 2010, Temel JS et al., published a landmark study that showed how early PC approaches, when compared to standard cancer care, led to less aggressive treatments with improved quality of life, less depression and increased survival in stage 4 non-small cell lung cancer patients.³ Despite the known benefits of PC, WHO reported that worldwide, only 14% of people requiring it have access to it.¹ This situation can be improved with greater commitment of governments working in partnership with corporate bodies and Non-Government Organisations (NGOs).⁴ Governments must therefore create national policies to steer the design and development of models of PC to suit the country's needs. With the rapidly ageing global population and the exponential rise in non-communicable chronic diseases (NCDs), the demand for PC services is ever increasing. WHO's 2019 survey of 194 member countries indicated that only 68% had some funding for PC and 39% reported that the services reached only 50% of the people in need.⁵

Scope and Practice of Palliative Care

As defined by the WHO, PC is applicable early in the course of an illness in conjunction with other therapies that are intended to prolong life, both in children and adults.¹ It was also explicitly stated in the WHO Global Action plan for Non-communicable diseases (NCDs) that comprehensive care of NCDs requires the access to PC services.⁶ Hence, PC is needed by all people who suffer from NCDs which are life-threatening including cancers, end-organ failures, neurodegenerative diseases as well as frailty in the elderly.^{5,7-9} Its role is not merely confined to those who are dying but should include those with longer illness trajectories but severe disease morbidity. Beyond NCDs, the role of PC is also recognised for communicable diseases such as HIV/AIDS, multidrug-resistant tuberculosis and most recently severe COVID-19.⁵ In 2014 the World Health Assembly passed resolution WHA67.¹⁹ to impress upon its members to integrate

PC within their healthcare systems to provide a continuum of care across all levels including hospital care, primary care, community and home-based care.⁷ Hence the practice of PC must be wide and far-reaching to provide equitable care to all in need both in rural and urban settings. It has been argued that PC is a human rights issue and is part of universal health coverage.^{5,9,10} In reality, however, worldwide there exists gross inequity with a lack of funding, human resource and essential medications to provide PC in poorer countries particularly in rural settings. The National Palliative Care Policy and Strategic Plan (NPCPSP) is an initiative by the Malaysian government to address this inequity and integrate PC into its local healthcare system.⁴

Lancet Commission on Palliative Care and Pain Relief

In 2018 the Lancet Commission on Palliative Care and Pain Relief used a methodology to assess the global need for PC called 'serious health-related suffering (SHS)' using mortality data for 20 conditions, adjusted for the prevalence of both physical and psychosocial symptoms. It reported that 25.5 million of 56.2 million people who died in 2015 experienced SHS and another 35.5 million experienced SHS due to life-threatening conditions. Majority (i.e., 80%) of these 61 million individuals lived in low-income and middle-income countries. These countries had very little access to any PC, and oral morphine for pain relief. More than 90% of paediatric deaths are associated with SHS and annually, 2.5 million terminally ill children around the world are in need of PC and pain relief. The report highlights the growing need for services to be developed equitably extending beyond urban centres.¹¹

Palliative care in Malaysia

In November 2019, the Malaysian Ministry of Health (MOH) launched the NPCPSP 2019-2030. The plan highlighted the development of PC in Malaysia since the field's inception in 1991 and the need for much greater efforts to be made in order to provide effective, equitable and sustainable PC throughout the country. The report documented that only seven hospitals under the MOH had resident specialists in palliative medicine and of these, only four had in-patient PC units. Apart from the MOH, four public teaching hospitals and five private hospitals also provide specialist PC services, all of them are located in urban areas. The NPCPSP recognises that, despite significant progress in the development of PC, it does not cover the full scope of PC; progress has been sporadic and lacking standardisation. In fact, services in rural areas are non-existent. There is no equity of PC in Malaysia.⁴

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It is recognised that a large proportion of PC services should be community-based, in order to facilitate care at home as research has shown that majority of people prefer home as their place of care and death.^{12,13} There are also many benefits of community-based care including improved quality of life and reducing overall cost of healthcare and hospitalisation.^{14,15} Despite this insight, community-based PC has received very little support for its development and at present most of this care is provided by 30 PC by NGOs that have been voluntarily established throughout the country. While these services are a blessing to the nation, the coverage is grossly inadequate serving again, mainly urban areas. To improve the situation, in 2016, the MOH initiated the development of domiciliary PC programmes at their health clinics, piloted in the states of Selangor, Perak, Penang, and Kedah.⁴ This is an important development but progress is slow in this due to the lack of funding and human resource.

The NPCPSP estimated the cost for developing eight new PC units in major hospitals with 160 domiciliary care team (not including operational cost in the MOH is expected to be RM38 million. It is estimated that twice this amount is needed to form such units throughout the whole nation. Specific annual funding for PC in the MOH is RM 7.5 million, with only RM 0.8-1.2 million awarded for PC as government grants to NGOs. This funding is insufficient to put in place a comprehensive integrated PC in Malaysia and an estimated increase of annual funding of upto 30.4 million RM for human resource, infrastructure, and purchase of drugs is required.⁴ PC services provided by nursing homes is very limited. The standard of practice of such services has neither been evaluated or documented in a central registry. There is a need to evaluate competencies of staff, availability of medications and resources for PC in these care centres.

Provision of palliative care: Models of care

The WHO public health model for PC is the primary framework for developing PC services. It emphasises the need for essential drug availability, PC education and implementation of PC services under an umbrella of government policy.¹⁶ Expanding upon this is also the need for human resource and funding.

There are many models of delivery of PC service and in general these models are built around the major areas of ambulatory clinics, home-based programs, inpatient PC units, and inpatient consultation services.^{17,18} These service delivery models may provide care at various levels of skill and complexity beginning with the basic PC approach which can be delivered by any healthcare service and evolving to generalist, specialist services and finally the PC reference centre.¹⁹ Lockett et al., conducted a rapid review of the elements of effective PC models and concluded that effective population-based PC models should include supporting case management through the integration of specialist PC with primary and community care services, and enable transitions across care settings, including residential aged care.²⁰

Lim LC et al., reported developing a community-based PC services in Kuala Lipis Hospital, Malaysia. They adopted the traditional public health care model which highlighted the need to foster greater leadership among health personnel

and community leaders in increasing accessibility of PC to the community.²¹ If this model is effective and sustainable, such a strategy could be extended to support home care in Malaysia.

Beyond service provision, novel models for funding are also important as the implementation of a national PC policy needs to be sustainable without relying entirely on government infrastructures alone. Greater corporate involvement and collaboration with other agencies, local government and NGOs are essential. A successful model in Uganda has demonstrated how a smart partnerships between NGO-run PC centres and the government, wherein the government provides essential medications, training and payment of taxes, has encouraged development and sustainability of PC services.²² In Malaysia, PC NGOs are estimated to raise some RM 7-8 million annually for maintaining operations while only about RM one million was given out as government grants.⁴ Much more needs to be done to support PC NGOs providing such essential services.

BURDEN OF DISEASE IN MALAYSIA

The National Health and Morbidity Survey (NHMS) of 2019 reported that NCDs in Malaysia, contributed up to 71% of premature deaths. The prevalence of diabetes was 18.3%; hypercholesterolaemia 38.1% and hypertension, 30% in 2019.²³ With the increasing prevalence of diabetes, hypertension and hypercholesterolaemia, it is unlikely that Malaysia will achieve target 3.4 of the United Nations Sustainable Development Goals in reducing premature mortality due to NCDs.²⁴ It can be inferred that this situation, cumulatively will add to the increasing need for rehabilitation and PC services.

Currently, about 150,000 people require PC services in Malaysia, and this is estimated to rise to 240,000 by 2030.²⁵ Using the serious SHS formula, it is estimated that 220,000 people would require PC annually. Similar estimates for children with SHS in Malaysia is around 30,000 annually.^{4,11} Only a small proportion of these children are cancer cases; a larger proportion being those with cerebral palsy, neurodegenerative, muscular dystrophy, and congenital malformations as well as inborn errors of metabolism who require longer term care. Paediatric PC which started developing in 2012 is lagging behind adult PC in Malaysia and to date only 4 paediatricians have specialised in the field.^{4,26}

NEED FOR FURTHER INTEGRATION AND GOVERNMENT SUPPORT

The WHO Global Action Plan for NCDs includes the integration of PC into the healthcare system to meet the goals of Universal Health Coverage stated in the UNSDG Target 3.8, as well as the goals of Primary Health Care in the Declaration of Astana, 2018.^{6,24} This plan is supposed to be adopted by the MOH of Malaysia.

Due to the isolated provision of PC services and inequitable care provided to the population, Malaysia was ranked 38 out of 80 countries in the Global Quality of Death Index study in

2015 falling behind countries such as Mongolia and Uganda.²⁷ In the recent second edition of the 'Global Atlas of Palliative Care' Malaysia was categorised as a level 3A nation meaning there has been limited progress in integrating PC into the healthcare system while our neighbours Singapore and Thailand have already achieved level 4A which are approximating integration.⁵

The NPCPSP report 2019-2030, admits there is much more to do, as Malaysia still 'lacks equitable and effective PC services to meet the acute needs of the Malaysian population'.⁴ Malaysia, as a signatory of WHA 67.19 resolution, urgently requires strategic implementation of workable processes, especially in the rural and remote areas.⁷

Working models aside, other gaps identified by MOH are the availability and dispensing of essential medicines, especially morphine, infrastructure, and human resources. In order to bridge these gaps, the NPCPSP has suggested an expanded healthcare framework with seamless merging of private and public sectors. It identifies 7 key strategies to integrate PC into the healthcare system which includes i) recognising PC as part of universal health coverage; ii) identifying PC needs of patients; iii) creating access to care and essential medications; iv) creating networks for continuity of care; v) investing in PC education at all levels; vi) encouraging community participation in PC provision and vii) establishing standards of care.⁴ These strategies are in line with recommendations by the WHO and Worldwide Hospice Palliative Care Alliance (WHPCA) in their blueprint for building integrated PC programmes and services which highlights the models and experiences of countries around the world where integration has been successful.¹⁹ While these strategies are very appropriately documented in the NPCPSP, there is an urgent need for all of this to be implemented as soon as possible.

Proposed Palliative Care Model in Malaysia

Fig.1 shows a proposed model of care to provide an integrated and comprehensive PC in Malaysia irrespective of place of care. The level of PC accessed will depend on the index case, which can range from hospital care to primary care and care in the home. For patients managed at home, the pattern of care may follow fluctuating phases in the progression of disease with spurts of higher level of service (including consultation with specialists) accessed from time to time. This would justify a seamless integration of levels of care to provide personalised and customised care. Current models of PC in Malaysia will need to be extended to rural and remote sites, including care of children. To support such services, the six pillars shown in Fig. 1 are to be enhanced. It is clear that to provide an integrated and comprehensive model, infrastructure and resources should be developed based on an analysis of needs of patients and family. One of the four foundation domains reflected in the figure would be appropriate funding. Greater political commitment and policy development will need to be the basis of effective and accessible PC services. Any design and development of a model of care needs to be integrated into the existing Malaysian health care system, with a smart partnership with public and private health facilities, to be sustainable in meeting the goals of the WHO.

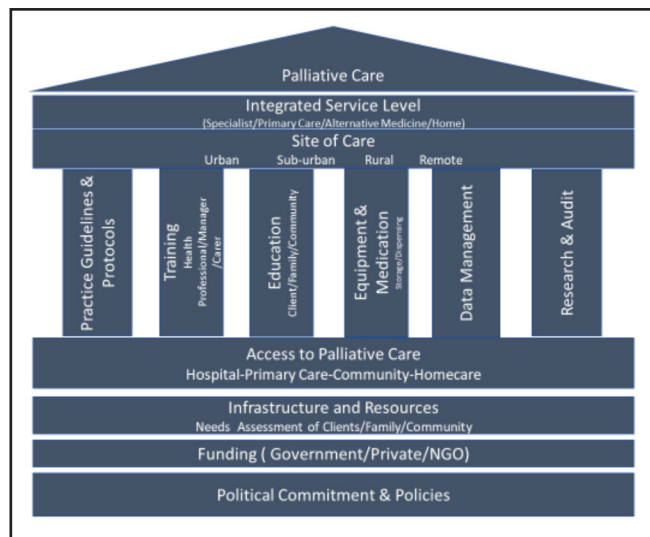


Fig. 1: Proposed Palliative Care Model in Malaysia.

Education and training for GPs, volunteers, and other stakeholders

Education and training are one of the key elements of the public health model for PC.¹⁶ In order to integrate PC into the healthcare system, education needs to be provided at every level beginning from public awareness to primary, secondary and tertiary healthcare levels.²⁸ Over the years, formal and informal training programmes have been conducted by the MOH, the Universities, PC NGOs, the Malaysian Hospice Council (MHC) and the local PC fraternity. However, this has hardly been enough to create sufficient human capital for the PC needs of the residents in the country. Public awareness about PC is grossly inadequate and in a study conducted by Hospis Malaysia, only 17.2% of respondents were able to describe PC correctly.¹² At the primary care level, all general practitioners (GPs) should have some basic knowledge and skill to care for patients needing PC. There is a dire need for more institutes of higher learning in Malaysia to offer formal training in PC. At the secondary level, hospitals offering basic specialist care should also be equipped to manage the PC needs of patients seeking surgical or medical care. Dedicated teams with more in-depth training in PC can provide this. Ultimately formal specialist training will provide centres of excellence where research and development can also be conducted.^{19,28}

At present, Malaysia has developed a fair amount of expertise in the field of PC with PC specialists, PC nurse specialists, an internationally acclaimed Hospice Centre (Hospis Malaysia) and even associate professors in PC in the universities. Hence much of the resources to train and educate others in PC already exist to some extent. What needs to be done is to bring these resources together to systematically provide a comprehensive PC education programme. An integrated blended learning approach with digital online learning is advocated in many developed countries and Malaysia must capitalise on this as well. Recently, University Malaya and the MHC commenced the Extension for Community Healthcare Outcomes Project

(Project ECHO) in Malaysia to reach out to PC NGOs throughout Malaysia. Project ECHO is a tele-mentoring programme developed by the University of New Mexico and is currently being shared throughout the world with the intention of helping clinicians to learn as they practice even when in remote areas.²⁹ As the COVID-19 pandemic has encouraged the use of virtual platforms for conducting webinars and conferences, the opportunities for tapping into international expertise has also become much more accessible and there is a myriad of online learning portals offering PC education to anyone.

One should not forget the training of volunteers who are also an important resource. With appropriate skills-building and coping enhancement they can help to provide a range of services including managerial, social, emotional, and physical care. It has been suggested that if a community can come together and provide care for one another at times of health crisis, this can significantly reduce the burden on healthcare systems and even reduce the cost of healthcare. This is the concept of “*compassionate communities*” and is an idea that must be looked into for Malaysia.³⁰

DATA MANAGEMENT

Robust data on PC services and the social and emotional impact on their family members is needed. Davies JM et al alluded to the value of routine data collected at personal, service, and geographical area level, drawn from death registry data, primary and secondary data, and other health parameters with particularities of the community at personal and family level. With digitalisation and documentation, MOH can draw uniform templates for generation of standard data that would help in analysis and service provision. Home deaths, specialist service, patient characteristics and healthcare processes will lend to measuring both gaps in service provision and measuring quality indices at all levels of care.³¹

The MOH e-Health programme will hopefully enable such data collection and if longitudinal medical records from the primary care setting can be collated electronically, it will provide enormous assistance for PC services, especially in continuing medical care from hospital-based treatment to PC at home.

CONCLUSION

The NPCPSP 2019-2030 launched by the MOH, though timely, needs urgent support and leadership to incorporate PC into the national health system. The current PC services in Malaysia are not sufficiently comprehensive to meet current needs and greater integration is required in a systematic manner to cover rural and urban areas.^{4,5,27} An urgent review of provision of pain relief and opioid availability is required.^{4,23} The power of individuals, families, and communities as partners-in-care needs to be further harnessed. Enhanced private-public partnership with greater contribution by GPs and primary care physicians is warranted. The institutes of higher learning in Malaysia should offer formal instructional training in PC all levels of personnel involved in the PC team. More research is

warranted in Malaysia to provide robust data on patients requiring PC, including the social and emotional impact on their family members. The systematic measurement of patient-reported indicators is an essential step towards people-centred health systems.^{4,31} In addition to a smart partnership, corporate bodies in Malaysia should also support public awareness. A comprehensive health economic study is urgently required by MOH to justify increasing budget needs for PC services beyond what is currently being provided and to find sustainable models of funding to incorporate PC provision by GPs, private healthcare facilities and NGOs. As serious health-related suffering will continue to rise, action must be taken now to ensure that proper care and support will be available to all peoples in Malaysia in the near future.

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