

Can Our Healthcare Be Improved With Better Stakeholder Engagement?

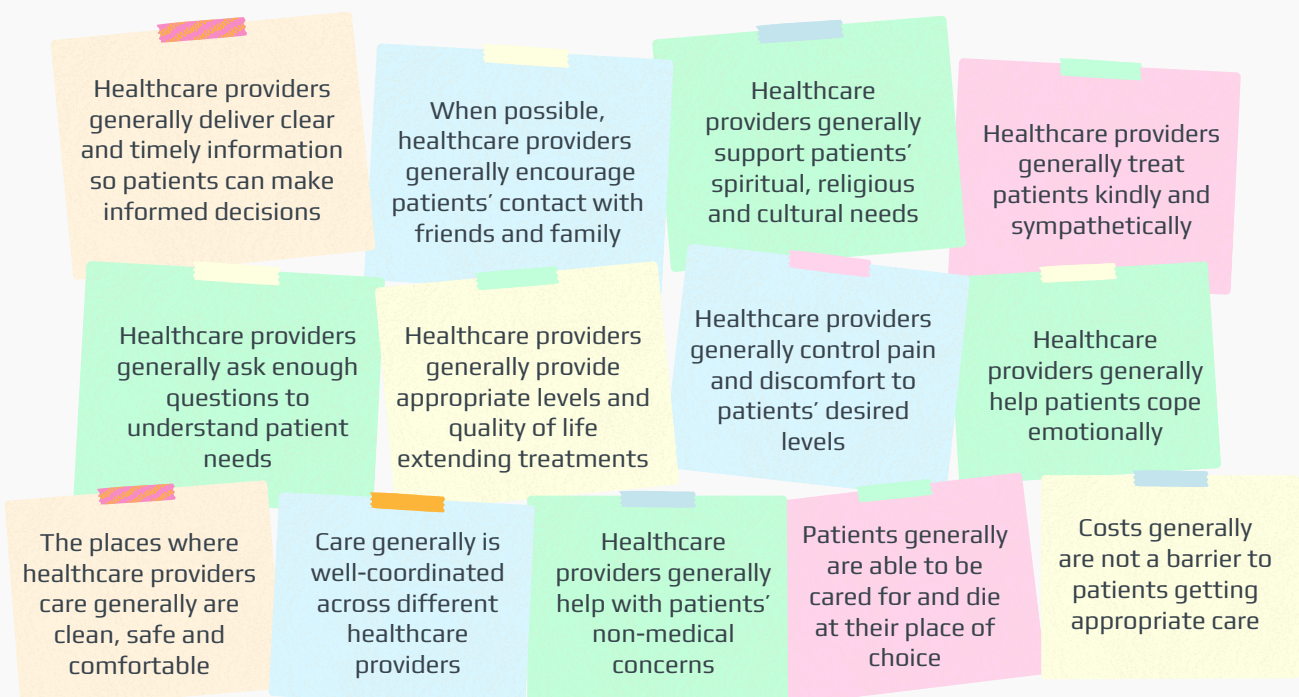
By Dr Ednin Hamzah, Chief Executive Officer, Hospis Malaysia

Malaysia is facing a challenge on multiple fronts. There are economic challenges, evolving political seats of power, an ageing society and healthcare issues growing exponentially even as we emerge from the Covid 19 pandemic. The reality is that we all reside in this nation we call home and to some extent we will share a collective future. Can we survive the present and have something to look forward to for the future?

In 2019, our Ministry of Health launched our National Palliative Care Policy and Strategic Plan 2019 – 2030 (1). We are now 5 years into our national strategy to improve care, are we providing better care?

There has been a slew of surveys of the Quality of Death and Dying (2010, 2015 and 2021) and the WHO Global Palliative Care Atlas (2014, 2020) of countries across the globe, and we have slowly seen Malaysia's ranking on how well we are living if we had a serious illness, until we die, being overtaken by most of our Asian neighbours, and many other countries around the world.

The Quality of Death and Dying Index 2021 looked at several indicators to inform on the survey, and to arrive at the rankings. The indicators are listed below:



The outcome of any policy is in the experience of the user. In this case, for the Malaysian public who seeks medical attention at our hospitals and clinics, perhaps we should be inquiring – “How has your experience been?” “If your experience has been below your expectations, why do you think are the reasons?” Policies are only effective if they are felt by those who should benefit from them.

The Lancet Commission on the Value of Death (Lancet 2022; Vol.399: 837-884) has stated that a key determinant in healthcare and end of life care is social determinants. It is natural when a loved one needs care, everything is utilised to this effect, often through emotional rather than rational reasoning. This often leads to chasing miracles and medical interventions that are futile, leading to further despair. For many this could result in dying in the ICU of hospitals distanced from their loved ones. Whereas if death can be accepted as the final outcome of life, and it is allowed to occur naturally, perhaps the patient and family can actually experience a good death – symptoms managed, patient is comfortable, with loved ones close by.

Living with an advanced illness carries a significant level of suffering and distress for patients and their families. They require access to effective palliative care at a place convenient and preferred by them – often this is in the community, where there is also access to social support from the community where they have built their lives. Good care in the community is only possible if policymakers recognise the important role other stakeholders such as non-government agencies play in serving the community.

Access to medicines is crucial. Majority of government hospitals will provide medication that can be taken by mouth but not injectable medicines when patients return home. What happens then if the patient is no longer able to swallow or has a condition where this is not possible e.g.: cancer of the head and neck? Will he have to return to hospital for his final days because his pain and other symptoms cannot be controlled at home because of a lack of medicines suitable for his consumption?

Families often require guidance and assistance when caring for a loved one at home. Whilst some are able to call in relatives and friends, others have to resort to hiring private nurses. These are often very expensive and unregulated.

There is sufficient evidence to show that good palliative care in the community has significant desirable outcomes. These include reduction in hospital admission, better quality of life and a higher chance of spending their final days at home. However, this requires a significant partnership between the community, government and other agencies such as community palliative care providers. Unfortunately, this coordination of care is not common in our country.

Partnerships though may still be forged between agencies that can envisage mutual community benefits. Hospis Malaysia will continue to work with resident communities, other non-government organisations, and corporates willing to offer volunteers and funding to try and ensure when someone within the community requires good palliative care, it may be provided. Whilst the Unity Government strives to assert itself, let us unite in the community.

Spotlight on Palliative Care Development in Sarawak

On 13th April 2023, a Memorandum of Understanding (MoU) was inked between Sarawak and the Asia Pacific Hospice Palliative Care Network (APHN), marking a significant step towards the rollout of palliative care training and educational programs across Sarawak to build capacity in the state. The MOU will enable the state to access regional expertise in palliative care, in particular through the APHN faculty who will provide training, technical assistance and education to healthcare professionals, equipping them over time with relevant skills and knowledge to provide effective palliative care to patients in need. The MoU will also enable Sarawak to collaborate with APHN and other partners in the state and the region to develop and implement policies and strategies to fit the local community in improving palliative care services. This will involve sharing best practices, exchanging information and experiences and working together to address common challenges.

Instrumental in coordinating this effort is Dr Sharon Choo, palliative care physician at the Sarawak General Hospital (SGH). After specialist training, Dr Choo joined Sarawak GH as the state's first specialist



Dr Sharon Choo pictured here during her training with Hospis Malaysia

in this field of medicine, with a mandate to develop its palliative care service.

Very early into her role there, she found that many of her patients had to travel long distances through arduous conditions to reach the hospital in the state's capital, Kuching, resulting in significant distress for both patient and caregiver, not to mention the financial resource needed to make the trip. And when their condition stabilized, most would want to return home to be with family. Many would also express that even if their condition deteriorates from thereon, they would prefer to remain at home. Others who remain in hospital for protracted lengths of time find themselves in a situation where they are unable to make that final journey home before they pass on, although that would have been their preference. It was then that Dr Choo realized that centralizing care in urban areas, and in particular in the capital in a state with almost 3 million people dispersed across a land area of almost 125,000 sq. km (almost the size of the entire Peninsular Malaysia) was not the solution. More needed to be done to build services in the communities where the people build their lives. She had seen this model of palliative care delivery in the community in Hospis Malaysia where she trained for 6 months, and felt strongly that delivering care where the people needed it most was essential.



A significant step towards the successful rollout of the palliative care training and educational program across Sarawak

A discussion with Hospis Malaysia's CEO, Dr Ednin Hamzah in his capacity as Chairperson of APHN and subsequent follow-up meetings between APHN Board Members, senior officials of the Sarawak State Health Authority and Sarawak's Deputy Premier, Prof Dato Sri Dr Sim Kui Hian, and leading figures from existing community hospices, eventually led to the drawing up of the MoU and its inaugural Lien Collaborative Palliative Care Workshop for Sarawak. 47 participants from three major state hospitals and 13 health clinics comprising of doctors, nurses and medical assistants attended, with the aim for attendees to be Master Trainers after the completion of three modules of the workshop. APHN faculty were drawn from as far out as Australia, Singapore and Kuala Lumpur to facilitate.

Together with her co-project manager, Dr Winnie Ling from Two Tree Lodge in Kuching, Dr Choo is working closely with APHN and its faculty to map out the phases of development to ensure that as many people in Sarawak as possible will have access to good palliative care. At this initial stage, teaching and training will be essential for key health workers so that they understand the principles of evidence-based palliative care and its early applicability in the course of a diagnosis of an advance illness and not just merely at the end of life.



Participants attending the inaugural Lien Collaborative Workshop for Palliative Care

"the essence of good palliative care is to treat the patient so that they live well and with dignity until the end. If that means that care needs to be localised and delivered in their preferred place, then we should strive to ensure that this is made possible"

- Dr Sharon Choo

They will then look to optimize existing resources to extend their reach over time, more healthcare personnel with responsibilities in the communities they work in will be trained, first to identify basic palliative care needs and then to address them. More complex cases may require support from more skilled professionals who typically reside in acute hospitals in urban areas, but it is hoped that eventually patients will not need to return to hospital, unless symptoms cannot be managed at home.

In her time at Hospis Malaysia and a community palliative care centre in Australia, Dr Choo has seen how with good training, experience and access to opioids and other medication, its clinical team who work with patients in the community have been able to handle a significant amount of their patients' symptom burden at home. She is therefore optimistic that with a united effort from all stakeholders, and the continued guidance from her colleagues in the region, this can be achievable in Sarawak. As Dr Choo expressed, "For after all, the essence of good palliative care is to treat the patient so that they can live well and with dignity until the end. And if that means that care therefore needs to be localised and delivered in their preferred place (often in their own community), then we should strive to ensure that this is made possible".

Communications Skills in Palliative Care Workshop: 8-9 July 2023

Effective communication helps build trust and rapport between healthcare workers, their patients, and their family members. This trust is essential in establishing a holistic relationship, which is crucial in palliative care. This skill enables doctors, nurses and social workers to understand the physical, emotional, and spiritual needs of the patient receiving care. By actively listening and engaging in open and honest conversations, healthcare workers can gather important information about the patient's preferences, care goals, and concerns. These are skills that need to be taught, trained and nurtured for many healthcare workers over the course of their career, and this is one of many such workshops that Hospis Malaysia runs to train palliative care health workers.

Workshop Facilitator Dr Rebecca 'Becky' Coles-Gale, a certified clinical and health psychologist working in the NHS in the UK with special interest in palliative care, kicked off Day 1 by encouraging the 60 attendees to bring their own experiences from their work settings to be depicted in various small group role play scenarios over the course of the training. By Day 2, participants were able to use ideas and techniques they learned, to apply to their workplace scenarios, giving them a learned advantage on making a difference to a particular interaction should they find themselves in a similar situation again.



Dr Becky used a story-telling approach to her teaching, going back to basics of communication, exploring participants' understanding of what communication is.

Participants brainstormed enthusiastically amongst their groups to propose solutions on best ways to facilitate difficult conversations and shared best practices from their varied working backgrounds to incorporate into their presentations. Values that they each brought with them – of fairness, respect, etiquette, ethics and others enriched their reflections, which were evident during their collective group presentations.

A vital topic in this communications workshop is 'understanding the barriers to communications' – be it, barriers in communication in the healthcare settings or workplace, or personal barriers. Communication breakdown is impossible to avoid, but knowing what to do when breakdown occurs is what sets a good healthcare worker apart from the rest, because it presents an opportunity to use the new skills acquired, to recognize, reflect and learn in order to improve the quality of care provided to a patient, their family and caregiver.



Activities using various forms of communications, having difficult conversations and presenting group discussion outcomes

"Instead of having consultations, healthcare workers should be having conversations with our patients, rather than just ticking a checklist each time the patient comes in for a consultation"

Another key point raised was the importance of practicing compassion in healthcare – which is not only crucial for fostering effective communication, but an essential component of patient-centered care, in addition to also preventing burnout among healthcare providers, because when compassion exists within healthcare workers, it is then available for everyone, patients and co-workers alike!



Groups activities kept participants engaged with thought-provoking topics and an opportunity to upskill

A key workshop takeaway that Dr Aaron Chiew, a palliative care trainee with the Ministry of Health was happy to learn was “grasping the concept of having a consultation versus having a conversation”. Dr Nik Natasha, another MOH palliative care trainee agreed and added “This idea has triggered a thought in me, that we (healthcare workers) should be having conversations with our patients, rather than just ticking a checklist each time the patient comes in for a consultation”.

Good communication skills contribute to improving the overall quality of care and the well-being of patients and their families during their challenging palliative care journey. Therefore, healthcare workers in this field need to be able to actively listen and show compassion; they need to recognize when communication breakdown occurs but still able to prevent long-lasting damage from souring relationship with patient and family, and above all, they need to be able to reflect afterwards. This is all possible through continuous learning like this, where they are able to keep abreast with the necessary skills.



Participants at the end of the two-day training on communications skills in palliative care

22nd Annual Hospis Malaysia Motor Treasure Hunt Crosses the Peninsular: 27-28 May 2023

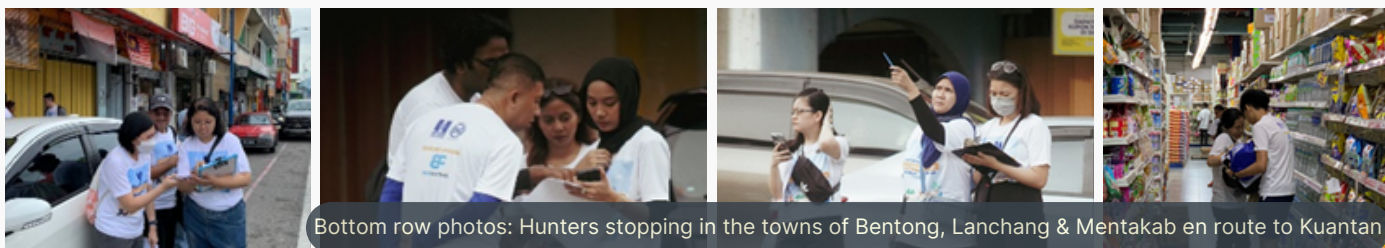


This year's Hunt to the East Coast city of Kuantan was a success thanks to participation by returning teams, a fresh crop of novice hunters, and the dedication plus hard work of our Hunt Masters Liew Kok Seng and YS Khong. Familiar faces graced the top 3 winning spots again but there is hope yet for other teams next year as more returning teams are steadily scaling up the prize ladder each year! Well done, to all veteran hunters and newbies alike!

We couldn't have done this without our sponsors - a big thank you to Cash Sponsors: Blue Fortress Sdn Bhd, Crowe Malaysia PLT, LBS Foundation, Great Eastern General Insurance (Malaysia) Bhd, Rainbow Lighthouse Kindergarten, Experian Marketing Services (Malaysia) Sdn Bhd and Boh Plantations Sdn Bhd; Prize Sponsors YTL Hotels, Thong Sia Sdn Bhd (SEIKO), Four Seasons Resort Langkawi, Swiss-Belhotel Kuantan; and Goody Bag Sponsors Amoy Canning (Beverages) Sdn Bhd, Nestlé Malaysia, Bijoux Food Company and The Lost Food Project.



Top row photos: Flag Off from Bangsar Village at 7:00am

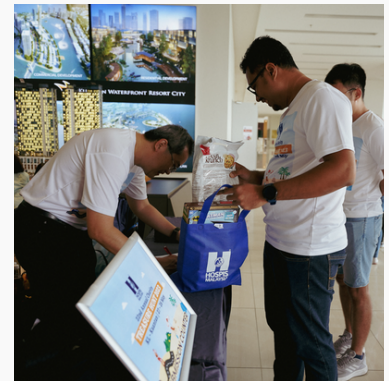


Bottom row photos: Hunters stopping in the towns of Bentong, Lanchang & Mentakab en route to Kuantan

22nd Annual Motor Treasure Hunt From KL to Kuantan: 27-28 May 2023



Teams checking in at Finish Control in Swiss-Belhotel Kuantan at the end of the hunt



Welcome Note by Hospis Malaysia Council Member Ms Lim Wai Yee



Winner of a Live Auction item celebrating her win



Some returning teams in happy spirits during the dinner and presentation ceremony



A team receives their prize



Hunt Master KS Liew with the winners of the 2023 Treasure Hunt



Post-dinner photo sessions



First-time hunters still in high spirits after a day of driving, walking, deciphering clues, solving puzzles and finding their treasures

Upcoming Events

Palliative Care Workshops

Using Cochrane Evidence in Palliative Care

2pm - 4pm | Online
Session 1: 16 August
Session 2: 23 August

To register, please click:
<https://hospismalaysia.org/cochranevidence23/>

Developing Resilience in Managing Challenging Clinical Situation

15 - 16 September

More info, please click:
<https://hospismalaysia.org/developingresilience23/>

UM-HM Paediatric Palliative Care Symposium

9 - 11 September
University Malaya, KL

To register, please click:
<https://hospismalaysia.org/paediatricpalliativecaresymposium/>

Clinical Ethics in Palliative Care

2 - 3 December

More info, please click:
<https://hospismalaysia.org/ethicsworkshop23/>

Grief & Bereavement

16 - 17 December

More info, please click:
<https://hospismalaysia.org/griefnbereavement23/>

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RUN FOR HOSPIS MALAYSIA
30 September - 1 October 2023

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<https://tinyurl.com/KLSCMXHM2023>



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WORLD HOSPICE & PALLIATIVE CARE DAY

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