POWERING UP PALLIATIVE CARE – WHAT'S NEEDED?

By Dr Jeremy Lim

Few would remember the "death houses" that were synonymous with Sago Lane in the 1950s, and in fact were said to be responsible for then-Prime Minister Lee Kuan Yew's reluctance to allow the establishment of hospices in Singapore. We have made much progress since those days and today, the palliative care landscape is effervescing with a healthy mix of hospital departments, non-profit hospices and day hospice services as well as academic institutions. Palliative medicine is taught in medical schools and there are professional bodies in the shape of the Section of Palliative Medicine Physicians (Academy of Medicine Singapore) and Chapter of Palliative Care Nurses (Singapore Nursing Association). However, what is the uniting strategy, the blueprint that binds and renders coherent all these disparate entities and initiatives?

The Need for a Plan

"Would you tell me, please, which way I ought to go from here?"
"That depends a good deal on where you want to get to," said the Cat.
"I don't much care where–" said Alice.
"Then it doesn't matter which way you go," said the Cat.
"–so long as I get SOMEWHERE," Alice added as an explanation.
"Oh, you're sure to do that," said the Cat, "if you only walk long enough."
(From Alice's Adventures in Wonderland, Chapter 6)

Sadly, Singapore lacks a national palliative care strategy which has been highlighted in the recent Quality of Death index developed by the Economist Intelligence Unit (EIU). For the sake of the more than ten thousand Singaporeans who need end-of-life care every year, we should prioritise correcting this anomaly. We have walked long enough.

The Good Death

Jack Welch, the legendary CEO of General Electric (1988-2000), famously described strategic planning as picking a general direction and implementing like hell. Ironically, it is that simple. What do we want to achieve, or in management speak, what is the "mission and vision"? In this, Health Minister Khaw provides clear guidance: "After a full and meaningful life, I certainly wish to die at home, among my loved ones, in familiar and peaceful surroundings." In the End of Life Care Strategy (2008) published by the NHS in England, the good death has four criteria: Being treated as an individual, with dignity and respect; being without pain and other symptoms; being in familiar surroundings; and being in the company of close family and/or friends. What of the vision for the country? Palliative Care Australia, the peak body for palliative care summarises the vision for Australia in nine pithy words – "Quality care at the end of life for all".

Whatever the form of the national palliative care strategy, the logical alignment to the mission and vision must be instantly obvious or we should be questioning the saliency of the strategy.

Before rushing headlong into developing a grandiose strategy that will suffer the ignominy of languishing in a bureaucrat's drawer, doomed to be discussed only within the hallowed halls of government, there are five guiding principles policy-makers would be wise to pay heed to:

5 Key Ingredients

Palliative Care is medico-social

The unfortunate administrative dichotomy into health and social ministries disadvantages holistic planning and encourages the silo mentality. Palliative care is in

equal measure a clinical effort (in pain relief, symptom control and the like) and a social movement. Even as we consider the very genuine need to ramp up on medical management in palliative care, we also need to blend this with recognition of the necessity for addressing psychosocial needs and providing for bereavement support. Furthermore, because palliative care is a social movement, public acceptance is vital and a generation of misinformation and ignorance about palliative care and the dying process will need to be overcome.

Inclusivity and Ownership

Any strategy process must be inclusive and expand beyond "experts" in palliative medicine to encompass societal representatives, ethicists and sociologists. A national task force comprising only health officials and clinicians will inevitably produce a lop-sided plan that fails to balance equally the medical and social aspects of palliative care. The importance of civic society also cannot be over-emphasised. The bulk of palliative care services in the community are provided today by Voluntary Welfare Organisations (VWOs) such as HCA Hospice Care, Dover Park Hospice and the like, and must be an integral part of the strategy formulation. In fact, I would even go further and propose a process akin to what was done by the Censorship Review Committee which draws its members from a wide spectrum of society and presents recommendations to the government to adopt. The palliative care strategy needs to be owned by the providers and the larger society with the government playing the adroit role of midwife and chief cheerleader.

"Holistic Analysis"

A common misconception amongst policy makers is that any community intervention must pass the test of "cheaper than doing it in the acute hospital". Hence, hospices, including home hospices are asked to benchmark their costs against acute hospitals and if the cost difference is insubstantial, policy makers question the "cost-efficiency" and wonder aloud why we don't just keep the patients in hospital. This mindset is puzzling as the two services are obviously different with different objectives and emphases. Should we not be asking instead what clinical and pastoral services are needed in palliative care, determine a reasonable rate and then benchmark the costs of their provision against other countries? Dean Kishore Mahbubani of the Lee Kuan Yew School of Public Policy writes of "holistic analysis" for a better Singapore and sums up, "simply relying on economic principles or on the forces of the market would be incomplete, if not downright wrong. Hence, in our public policies, we must give increasing weight to the intangible."

Why shouldn't Singapore be at the top of the rankings for "quality of death"? We are a small and compact city state, have some of the best trained palliative care professionals in the world, enjoy a milieu of "Asian values" and strong family bonds and have a particularly passionate Minister who has very courageously overcome taboos and spoken on multiple occasions about the "good death".

Clarity with Granularity

Minister Khaw three years ago described four Ministry efforts in palliative care: Growing palliative medicine as an "attractive and effective medical sub-specialty"; extending palliative care beyond oncology patients; ramping up nursing and allied health manpower and finally; educating the public about hospice and end-of-life care.

This high level guidance would be sufficient for large and well-resourced acute hospitals that can pick the ball up and run, but for VWO hospice providers already struggling to meet day-to-day demands, a national palliative care strategy needs to go beyond generic principles and motherhood statements. Questions like, "What should be the mix between inpatient hospices, day hospices and home hospice services?", "How should palliative care be organised in the model of Regional Health Systems?" and "What is the role of the Ministry of Health (MOH) viz a viz the Singapore Hospice Council and the individual providers?" are all pertinent and need to be answered clearly so that the providers can make organisational action plans aligned to the national imperative.

"No Money, No Mission"

It may seem crass to discuss finances so blatantly, but the government needs to be upfront on funding quantum and sources. The English spend £588 million a year on palliative care or over £1,100 per dying person (The National Health Service's somewhat meagre £88 million is heavily supplemented by philanthropic monies of £400 million and another £100 million worth of volunteer services) while the MOH commits about S$5 million a year which works out to just under S$300 of government funding per dying person. If we aspire to provide palliative care of similar quality to the UK to ALL Singaporeans who need palliative care, then assuming pound-dollar parity for convenience, a back of envelope calculation puts the additional money needed through more government subsidies, philanthropy and patient fees at almost S$14 million a year. I do not know whether this is too high a price to pay for world-class end-of-life care but whatever the amount of funding commitment, the palliative care providers need to know so that they can cut the coat according to the cloth. The providers also need to know what services will be funded by the government; for example, home hospice care for patients' psychosocial needs are not currently funded by the government.

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