

Life
Before
Death



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Doctors and nurses report inadequacies in medical & nursing education, training, communication and healthcare system support for the terminally ill in Singapore

Almost all doctors and nurses think that hospice palliative care¹ should be made readily available but 74% of doctors and 46% of nurses feel that they do not know enough about this area of care

¹ Hospice palliative care is a holistic approach to caring for patients going through the last stages of their lives. It aims to meet all needs (physical, emotional, psychosocial and spiritual) so as to alleviate suffering and maximise quality of life for patients and their loved ones.

Lien Foundation's survey of doctors & nurses reveal critical needs for action to improve care for the dying

Singapore, 18 June 2014

1. What do doctors and nurses think about death and dying in Singapore? Their insiders' view of the situation gives us clues to navigate the future of dying in Singapore.
2. The **Lien Foundation** commissioned Blackbox Research to examine for the first time, the death attitudes of over 200 doctors and 400 nurses in Singapore. The survey conducted from February to April 2014 probed their views about death and dying, and their levels of awareness and receptivity towards hospice palliative care. More than half of the respondents were from public hospitals. This follows the general public death attitudes survey released in April this year.

3. “Doctors and nurses are frequently the guardians of care at the end of life, guiding patients and their families through a challenging time. This survey provides their perspectives on care for the dying, and an assessment of the critical weaknesses in our healthcare system, especially in the area of professional training,” said Mr Lee Poh Wah, CEO, Lien Foundation “We’ve got to make palliative care part of our healthcare system’s DNA. Clinicians need greater competence, confidence and inspiration to provide the kind of end-of-life care we would wish for ourselves and our loved ones.”

Doctors and nurses value importance of hospice palliative care

4. Almost all doctors (95%) and nurses (94%) surveyed considered hospice palliative care important for those with life-threatening illnesses. Close to all the doctors (98%) and nurses (95%) want hospice palliative care to be made readily available. Majority of the doctors (97%) and nurses (90%) agree that the public needs to know more about hospice palliative care, and 88% of them regard end-of-life care training as important in basic medical and nursing education.

Doctors and nurses need to be more familiar with hospice palliative care

5. However, the survey revealed 74% of doctors and 46% of nurses felt medical professionals do not know enough about hospice palliative care. Of those surveyed, only 38% of doctors and 45% of nurses reported being familiar with it. Even among those with frequent contact with terminally ill patients, only 44% of doctors and 59% of nurses said they were familiar with hospice palliative care. This suggests a gap in the knowledge needed to support patients in end-of-life matters.

Basic medical education not enough

6. When asked if their basic medical or nursing education prepared them to support patients with life threatening illnesses, 62% of doctors and 38% of nurses said it was not enough.

“The focus during my time in medical school was all about management options first, and palliation was taught or considered as the last resort when all else failed. Thus, I feel that from the outset, the preparation of our doctors is sorely lacking in preparing doctors for end-of-life issues, as we are taught to avoid and not embrace it, and then we see that death is more the norm than the exception when we enter into the workforce.” Doctor Respondent

In addition, only 17% of doctors and 26% of nurses agreed they have sufficient training in hospice palliative care.

Enhance training for medical students

7. Associate Professor Yeoh Khay Guan, Dean of Yong Loo Lin School of Medicine, National University of Singapore (NUS) said, “Palliative care aims at preventing or relieving pain and suffering, and to improve the quality of life for patients with life-threatening illness. The survey findings highlight that many physicians and nurses feel more training in palliative care is needed. Training in palliative care starts in medical school and continues in postgraduate training and continuing professional education. Currently, undergraduate students at the NUS School of Medicine receive training in palliative care from the third year of studies. We plan to expand and enhance the training in palliative medicine from the third to the fifth year of studies, in a variety of practice settings including hospices, home care and in hospitals.”

8. At Nanyang Technological University's Lee Kong Chian School of Medicine, medical students will receive hospice palliative care training in their fourth year of studies. Duke-NUS Graduate Medical School provides one day of exposure and training in hospice palliative care for their students.

Little hospice palliative education for nurses

9. The amount of training in hospice and palliative care for nurses in Singapore is dismally low. Palliative care is an elective component for enrolled nurses. Nursing degree and diploma holders here receive four to six hours of lectures in palliative care in their entire course. In the U.K, nurses in degree courses like Manchester University get two weeks of classroom teaching and one week attachment at a hospice.

10. Ang Mo Kio-Thye Hua Kuan's Director of Nursing and Associate Professor Edward Poon said, "Nurses have a huge role to play in the delivery of hospice palliative care, especially with the increasing focus on community & home-based care. We need to better equip trainees and all nurses with basic knowledge of hospice palliative care," said Associate Professor Poon. "The culture, values and environment in our hospitals and places of care need to encourage and foster greater openness and discussions about the end of life. We can also look at how to support and create more opportunities and platforms for nurses to put into practice the principles of palliative care, in whichever area of their specialty."

11. The path to equip the nurses will be a steep one. This calls for a deeper look into what is needed to allow for nurses to play a more active and constructive role in the care of patients. Even though nurses have higher patient contact time, only 53% of nurses surveyed had talked about hospice palliative care to their patients, while 82% of doctors have done so. When asked why they did not talk about hospice palliative care, more than a third of the nurses said they did not know enough about hospice palliative care to recommend it.

More training, more talk

12. The survey suggests that doctors (96%) and nurses (68%) who encountered terminally ill patients more often and were more familiar with hospice palliative care were more likely to talk about hospice palliative care with their patients. This points to the importance of equipping doctors and nurses who are in high contact with critically ill patients, such as those in the areas of oncology, ICU and geriatrics, with palliative care knowledge and training, as well as communication skills.

13. Associate Professor Pang Weng Sun, Vice-Dean Clinical Affairs, Lee Kong Chian School of Medicine at Nanyang Technological University (NTU) agrees, “We need to encourage our staff to engage patients and families more in conversations on end-of-life care – to understand their needs, concerns, anxieties and wishes – and redesign care that focuses on what is important to them, and not what we think is medically best for them.”

Need to improve skills in talking about death and dying

14. The issue of communication with patients about death and dying is an important one for doctors and nurses - patients look to them for advice on what to do, and what the available options are when death is near. The survey shows that half the doctors and a third of the nurses surveyed were comfortable discussing death and dying with their patients in their professional capacity. However, there is room for improvement. A doctor respondent observed:

“Healthcare professionals are also uncomfortable talking about death - the healthcare system has been designed to go all out in spite of futility in certain clear cut cases, that treatment would be futile. Sometimes, along the way, patients or their relatives or even their doctors realise that they can't do any more medically for their patients, but they are not empowered to pull the brakes to stop the journey of ever more tests and treatment. Other times, there is denial on the part of the patient and/ or relatives, which compounds their healthcare journey leading to increasing costs and more suffering for all involved.”

15. These results and feedback highlight the effects of poor communication.

Another doctor respondent captured it this way:

“Doctors may not want to bring up the subject of palliative care in case patients/relatives think they are giving up on treatment and hence referral is made to the palliative care team when the condition is really terminal and the patient has undergone a lot of pain and suffering. The outcome is that patient and relatives may not have time to consider how best they want to handle the process of dying.”

16. For dying patients, the time of referral to receive palliative help is crucial. Dover Park Hospice, one of Singapore's main providers of in-patient hospice care, reported that 2% of patients who were referred to the hospice died before assessment, and a further 21% died before admission into the hospice.² Singapore's biggest home hospice care provider, HCA Hospice Care noted that 2.6% of its patients died with less than a day of care and about 15% of patients passed away within a week or less of receiving care.³

² Dover Park Hospice 2012-13 Annual Report, page 11

³ HCA Hospice Care and its 2012-13 Annual Report.

17. This issue warrants a closer examination by doctors, nurses, hospitals and hospices on the timeliness and number of patients being referred to palliative care. When asked to evaluate hospice palliative care in the survey, just about 60% of the doctors and nurses rated it as 'good' or 'excellent'.

Weaknesses in healthcare system for the terminally ill

18. To better understand how the present healthcare system could better support the needs of the dying and terminally ill, respondents were asked to identify the weaknesses in this area of care. The most often cited weaknesses were: Insufficient training and a shortage of trained manpower, lack of information on hospice palliative care, limited hospice facilities and the issue of cost.

19. The deficit in training was highlighted by a doctor this way:

“[There is] insufficient training of health professionals; clear pathways for patients who would not benefit from care in an acute hospital so these patients go direct to a care facility which could handle end-of-life care with backing/ guidance from MOH. [We need] expansion of the palliative care workforce - nurses, allied health and doctor and integration of palliative care in geriatrics training, family medicine training, medical school and residency training.”

20. In addition to the need for more trained professionals, respondents also highlighted how greater information and awareness could make a difference.

For instance, a nurse urged:

“... awareness of availability of palliative care should be informed as early as possible. During times of distress [at later stage of illness] it becomes a sensitive issue, and makes it difficult for patient and family members to accept new information, especially if it concerns end-of-life caring.”

21. Many respondents brought up the dire need for more hospice facilities. A doctor said:

“In a fast ageing population, [there are] concerns are about the growing need and inadequate supply (staff, facilities, etc.) of hospice and palliative care services to catch up with the demand of the increasing number of patients. For example: a) Not many doctors/ nurses are interested to dabble in palliative care - difficulty recruiting staff. b) Long waiting list for patients requiring in-patient hospice beds/ services, to the extent that patients sometimes die in acute hospitals.”

22. Affordability and the cost of care was another key systemic weakness highlighted by respondents. In the words of a doctor:

"Funding mechanisms limit patient's decision for inpatient hospice transfers – e.g. CSC card holders are not eligible for funding, resulting in them opting to stay in acute hospitals... Insurance coverage usually precludes inpatient or outpatient hospice coverage. The Pioneer Generation package did not look specifically at this area"

23. The root of these weaknesses indicates the need to recognize and re-prioritise resources towards services for the dying, that are deemed “un-profitable”. A nurse throws the spotlight on this:

“End-of-life care is deemed as an "unprofitable" business. Human Resource Management and Finance have openly classified it so. In order for this essential service to take off, the senior management needs to be educated that not every service in the hospital must be price tagged. If manpower and resources are only allocated to profitable services - palliative medicine and end-of-life related services will take a back seat.”

Refer to Annex A for a list of other weaknesses highlighted by respondents.

Common death attitudes, different preferences

24. Majority of the doctors and nurses, like most of the public surveyed, wish to die at home. However, compared to 77% of the public who would still want to die at home despite insufficient support from medical professionals, just 35% of doctors and 54% nurses were of the same view.

25. While the public's top priority was to "ensure my death is not a financial burden to family members/loved ones", this concern was ranked second by the doctors and nurses. Ranked first on the list of these practitioners was the desire "to have control over pain relief and other symptom control", which was the second top-most priority for the public.

26. The professionals also differed from the public in their views of care support and prolonging treatment. While 42% of those in the public survey said they would like to receive life-prolonging treatments right up to the end of the terminal phase of an illness, only 7% of doctors and 21% of nurses expressed similar intention.

Scale up training and education, conversations & awareness in hospice palliative care

27. The survey findings present opportunities for the medical and nursing community as well as policy makers to examine and address the underlying issues to improve the quality of death in Singapore. The areas of action include:

- Enhancing basic medical and nursing education as well as continuing professional training to increase the skills and knowledge of hospice palliative care of doctors and nurses.
- Equipping all doctors and nurses with the skills of how to talk about death and dying with their patients.
- Incorporating palliative care principles in *all* healthcare settings, and fostering a culture and environment that supports better end-of-life care.

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Annex

- A Weaknesses in healthcare system in supporting the dying and terminally ill
- B Palliative care expertise and education in Singapore
- C Highlights of the Doctors and Nurses Survey

ABOUT THE LIEN FOUNDATION

www.lienfoundation.org

The Lien Foundation is a Singapore philanthropic house noted for its model of radical philanthropy. It breaks new ground by investing in innovative solutions, convening strategic partnerships and catalysing action on social and environmental challenges. The Foundation seeks to foster exemplary early childhood education, excellence in eldercare and effective environmental sustainability in water and sanitation.

In its mission to advance eldercare, the Foundation advocates better care of the dying. One of its flagship programmes, the Life Before Death initiative, was first conceived in 2006 to create greater public awareness about end-of-life issues in Singapore. It sought to de-stigmatise death and dying by spurring various 'die-logues' with the use of social media, art, films and photography and advocacy through research. Creative projects such as the *Happy Coffins*, *The Last Outfit*, *Obitcheery*, *Both Sides Now* and "Die Die Must Say" getai got people to confront their own mortality in unconventional ways.

The initiative has since gone beyond Singapore. In 2010, the Foundation commissioned the first-ever global Quality of Death index ranking 40 countries on their provision of end-of-life care. In 2013, the Foundation launched the inaugural international Design for Death competition that presented innovations in deathcare for the future.

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ANNEX A

Weaknesses in healthcare system in supporting the dying / terminally ill

Open-ended question:

In your opinion, what are some of the weaknesses in the current healthcare system in supporting the dying / terminally ill?

Weakness	Doctors (%)	Nurses (%)
1. Insufficient training / Shortage of trained Hospice Palliative Care staff	24	20
2. Lack of public information on Hospice Palliative Care	21	22
3. Not enough hospice facilities/ Shortage of beds	17	11

4. Affordability	16	5
5. Discomfort talking about Hospice Palliative Care	14	18
6. Lack of Government funding/support	8	4
7. Perception that Hospice Palliative Care is giving up on fighting the illness	5	2
8. Late referral of Hospice Palliative Care	5	2
9. Lack of spiritual/psychological support	2	5
10. No comments	4	14

ANNEX B

Palliative Care Expertise and Education in Singapore

Table 1: Doctors & nurses trained in palliative care in Singapore

Number of palliative care medicine specialists	46
Number of doctors currently receiving training for Palliative medicine subspecialty	15
Number of doctors⁴	10,953 (of which 38% are specialists)
Number of Advanced Practice Nurses in palliative care	6 (+ 3 in training)
Number of registered nurses trained in palliative care	72
Number of nurses trained in palliative care⁵	600
Number of Registered and Enrolled Nurses⁶	35,829

Table 2: Medical education in palliative care

Amount of training in palliative care given to students in their entire medical course

NUS Yong Loo Lin School of Medicine	4 days
Duke-NUS Graduate School of Medicine	1 day (Clinical Core programme)
NTU Lee Kong Chian Medical School	One week

⁴ Statistics published by Ministry of Health (as of end 2013):

https://www.moh.gov.sg/content/moh_web/home/statistics/Health_Facts_Singapore/Health_Manpower.html

⁵ "More trained palliative care nurses", The Straits Times, pg 13, 11 August 2013

⁶ Statistics by Ministry of Health (as of end 2013)

Table 3: Nursing education in palliative care

Amount of palliative care training given to nursing students

Enrolled Nurses - Nitec in Nursing, ITE	Elective: 3-hour lectures
Registered Nurses - Diploma in Health Sciences (Nursing), Ngee Ann Polytechnic / Diploma in Nursing, Nanyang Polytechnic	4-6 hours lectures
Nursing degree National University of Singapore (NUS) Bachelor Of Science (Nursing) / Bachelor Of Science (Nursing) (Honours) Singapore Institute of Technology (SIT) - University of Manchester Bachelor of Science with Honours in Nursing Practice	4-6 hours lectures 4 weeks: - 2 weeks lectures - 2 weeks practicum

Lien Foundation Attitudes on Death Survey

Blackbox Research was commissioned to conduct the surveys as part of a follow up to Lien Foundation’s 2009 poll on death attitudes in Singapore

About the Study

The first wave of the survey was conducted amongst the general population of Singaporeans to gather perceptions on death and dying and the level of awareness and receptivity towards hospice palliative care. The results of the study findings were presented in early 2014. This study is the second instalment of the study, examining the views of doctors and nurses.

Research Methodology:

Survey Methodology

Doctors: Online survey (n=207)

Nurses:

Online surveys (n=362); Self-completed surveys (n=63)

Responses were garnered via invitations through the Singapore Medical Association, Singapore Nurses Association & other networks within healthcare institutions.

Data Collection Period:

Between the period of February to April of 2014.

Nationality	Doctors	Nurses	Place of Work	Doctors	Nurses
Singaporeans	85%	78%	Public hospital	58%	71%
Foreigners	15%	22%	Private clinics/hospitals	32%	2%
			Others	4%	5%
			Polyclinic	3%	14%
			Palliative care setting	3%	8%
Years of Experience	Doctors	Nurses			
< 1 year to 10 years	33%	46%			
> 10 years to 20 years	29%	20%			
> 20 years	38%	34%			

In this study, ‘palliative care setting’ comprises community hospitals, nursing homes, home medical / nursing services, day care and hospices.