

Doctors are caught between ensuring patient autonomy and respecting families' wish for non-disclosure and collective decisions

Pioneering NUS study unveils what Singapore doctors say about caring for the dying

They express concern about the consumer-driven healthcare system and oppose euthanasia and physician-assisted suicide

Singapore. 4 September 2011.

1. The study entitled **“What Doctors Say About Care of the Dying”** unveiled key challenges to the improvements of end-of-life care in Singapore. Commissioned by the **Lien Foundation**, this is the first empirical study of ethical, legal and social issues in medicine conducted by the **National University of Singapore’s (NUS)** Centre for Biomedical Ethics. The study surveyed the views and attitudes of 78 doctors from the private and public sectors, including general practitioners and specialists from a wide range of practices. It is intended to educate, inform and stimulate debate amongst the doctors, public, policy makers and lawmakers, and develop consensus on standards of care.
2. One of the strongest themes revealed by the research was the role of the family in decision-making at the end of life. Doctors and families have divergent ideas about what it means to care for the patient who is at the end of life, particularly in disclosing to patients a diagnosis of terminal illness. Doctors grapple with the family’s preference for protective non-disclosure, which often leads to terminally ill patients being excluded from end-of-life discussions or even from making their own healthcare decisions. Tensions between doctors and families of patients arise when Western-based laws come into conflict with the Asian practice of collective decision-making in families, local values and cultural norms.
3. In the study, doctors raised their concerns about how no single healthcare practice has a good overview of a patient’s overall health and wellbeing. They highlighted the

need to debate the healthcare system openly for new ideas and policies about the fairness of access to good healthcare, and seamless and appropriate care for patients and families.

4. In cases of medical futility or competent patient refusal, most doctors interviewed said that it is morally acceptable to withhold and withdraw extraordinary life-sustaining treatment but hastening death was not acceptable. Almost all doctors disapproved of euthanasia and physician assisted suicide

Need to advance the policy and practice of end-of-care

5. Presently, there is very little research to guide the development of policy and practice of end-of-life care. On why the Foundation commissioned this study, its Chief Executive Officer, Mr Lee Poh Wah said, “Doctors are more than highly skilled restorers of health and relievers of suffering. They have a role as society’s confidants, guides and guardians of the end of life. We want to surface their collective voice on the clinical, policy and ethical quandaries they encounter in their care of the dying.”
6. He added, “Doctors not only carry the dual burden of disclosure and advice, they also come under numerous pressure points, like having to weigh the implications of healthcare costs for the patients and society, and coping with the taboo of talking about death and moral dilemmas of suffering”. The study is part of the Foundation’s mission to improve care for the dying, an effort started in 2006 with its Life Before Death initiative.

Research study to stimulate debate and discussion

7. The study’s principal researchers are Assistant Professor Jacqueline Chin and Visiting Senior Research Fellow Dr Jacinta Tan from NUS Centre for Biomedical Ethics (CBmE). Together with Associate Professor Terry Kaan and Assistant Professor Tracey Evans Chan from the NUS Faculty of Law, they used a qualitative interview method for the study that took place over ten months.

Key observations from the study

8. The researchers summed up their key observations of the doctors' perspectives and attitudes on care for the dying:
 - **Doctors see themselves as having the responsibility for deciding when medical science is no longer going to help the patients recover, to signal when the goal of care should shift from cure to comfort and quality of life, and to prepare patients for end of life. The religious beliefs of patients and their families as well as Singapore societal attitudes, however, do affect how well these tasks are achieved.**
 - **The principle of patient autonomy, well accepted in Western developed countries¹, is hard to apply in Singaporean family culture. The Singapore family favors collective decision making, and this can interfere in the doctors' duty of care in providing the patients with information about their diagnosis and involve them (patients) in healthcare decisions.**
 - **Our current healthcare system is ill suited to patients who want to die at home because of the lack of financial, social and physical support for this, e.g. financial system that subsidises acute care, lack of caregivers at home and logistical problems in certifying death at home.**
 - **Euthanasia and physician-assisted suicide is largely disapproved of and almost all doctors do not want their profession to have any part in such acts, though many specific cases of suffering do trouble doctors.**

The law and medical practice at odds

9. In Singapore, doctors find that they have to involve families in decision-making for most patients, especially those who are elderly and legal minors. This interferes with their duty to provide patients with information about their diagnosis and involve them in healthcare decisions. One of the most difficult ethical issues doctors face is the issue of withholding their diagnosis from patients at the family's request. While

¹ The principle of autonomy, as generally articulated in medical ethics and law originating in Anglo-American and Western European countries, enjoins respect for an individual's right to self-determination, privacy, confidentiality and bodily integrity.

the legal position makes it clear that doctors have an obligation to give full and frank disclosure to their patients, they often find that they need to work hard on family members to be allowed to talk to patients truthfully. One of the interviewees related how the law and actual medical practice seem to be at odds:

"... on one hand our laws seem to suggest one thing i.e. best interest as decision, but on the other hand, clinical practice seems to always send the message that family here in Singapore are of prime importance."

10. Both the doctors and patient's families want to do their best for the patient but so often the law and ethical codes are in contradiction to local values and cultures. Doctors often find themselves in difficult roles as umpires or referees between patients and families and the system. They struggle with how to reconcile these in particularly emotionally laden and stressful end-of-life situations. The study quotes a doctor who illustrates his problem:

".... sometimes we do have difficulty telling patients their diagnosis, much less making decisions. You can't make decisions when the patient doesn't know the diagnosis. That is a very common problem that we face, and usually the families are protective and don't want them to know how ill they are, because they don't want to make them feel worse. So it stops there. We need to make all these very difficult decisions about further medical care... It is very hard. We need to use our families as surrogates, based on their understanding of the values of the patients, to make all these very unilateral decisions. So, that is in itself quite a challenge."

11. With regard to Singapore law, Associate Professor Terry Kaan and Assistant Professor Tracey Evans Chan noted, "... although relevant family members should be consulted before decisions are made, there is no default legal authority for them to make decisions for adult patients. The exception relates to minors (those under 21 years), in which case parents or guardians have decision-making authority; but even then, the views of 'mature minors' should not be discounted. They may have authority to, at least, consent to medical treatment on their own."
12. The frequent scenario of collective family decisions and doctor-family 'collusion' raises the question as to whether our *current laws should be reviewed*. In Japan, patient autonomy is respected by a patient's advanced directive for disclosure, where he or she can choose a family member to receive the doctors' diagnosis on his or her behalf. Currently, there are no public guidelines in Singapore for doctors to deal with confidentiality, fertility and end-of-life issues.

Distrust about motives when it comes to end-of-life care

13. Doctors raised other issues concerning societal attitudes to death and dying which have a major impact on how doctors treat patients at the end-of-life. Doctors observed that families in Singapore find it difficult to suggest to their relatives that they should make practical preparations for death such as writing wills or stating wishes concerning terminal care, because they would often be accused of wishing them dead or wanting their property.

14. Religious beliefs of patients and their families also affect how well a patient faces death. Some religious and ethnic communities are better able to face and prepare for death, while others find it a taboo to be avoided. Doctors who understand their patient's cultural and religious views and attitude towards death and dying, are better equipped to meet their end-of-life care needs.

Consumer-driven system pose challenges to providing better end-of-life care

15. In addition to such attitudinal factors, doctors expressed their concerns that Singapore's general healthcare set up and financial system may not fit the needs of patients at the end of life, especially those who have long-term chronic healthcare needs. It is paradoxically cheaper and easier for patients to rely on subsidized care at acute hospitals than on community or home care because such services get less subsidies or support. In the words of one of the doctors interviewed:

“A lot of our current subventions [government subsidies] are geared toward inpatient care. While they can gain financial support much more easily for treatments in the hospital, when it comes to patients spending time at home or in the community hospitals the funding dries up, because funding is directed to the hospital itself.”

16. Due to the Singapore co-payment system, families are under considerable financial burden to care for those at the end of life, especially when their loved ones suffer from chronic, slow or protracted illnesses. Many patients exhaust their funds by the time they are ready to consider step-down care or hospice care. Doctors expressed their concern that the burden of care, including financial debt, can pass on from one generation to another.

Opposed to euthanasia and physician-assisted suicide (PAS)

17. Euthanasia and PAS is largely disapproved of and almost all doctors do not want any of their profession to have a part in this, though many specific cases of severe suffering do trouble doctors. In response to a suggestion that there should be a public debate over the question of allowing euthanasia or PAS, a doctor said:

"...my view is that, to even have to debate physician-assisted suicide or euthanasia is a proxy debate, really. Why isn't palliative care better than it is? That's my view. You know, I mean, if palliative care was perfect and life was really pleasant right up to death, then why would anybody clamour for physician-assisted suicide? It makes no sense, because... you look at the reasons why people are clamouring [and] it's all about human dignity, it's all about pain and suffering, it's all about utility and all that, right? But if end-of-life care and palliative care were as good as it should be, these demands would evaporate."

Conversation needs to continue

18. "This ethics study has thrown up many questions," said Lien Foundation's Mr Lee, adding, "It sets the stage for public discussion and opportunities to foster community wide solutions to the complex and vexing issues we face. Hopefully, a consensus may be reached to improve the standards, guidelines and desired practices in end-of-life care." The way the doctors responded in the study is a positive sign. Assistant Professor Jacqueline Chin said, "Jacinta Tan and I saw many doctors just going off their night calls, or making time in between seeing patients in their packed private clinics. They would assure us, 'It's ok, this is important. Let me think about your question.' They spoke with great feeling for their patients' families, and their visions of a caring healthcare system. What we have recorded are the perspectives of deeply committed professionals and their contributions to medical ethics in Singapore. To sustain the ethical practice of medicine here, the conversation needs to continue with various stakeholders and the wider public."

19. Fellow researcher Dr Jacinta Tan agreed, "It's immensely rewarding to conduct qualitative research with doctors on this subject. This type of research allows me as an ethicist to 'get real' by connecting with fellow doctors and to explore with them in depth what their views on end-of-life issues are. I also find out what their experiences are which shape these views. The best thing about this method of research is that Jacqueline Chin and I talk to all sorts of doctors, not just the experts in the subject, and this leaves room for us to be surprised by the things that might

come up. Often the doctors themselves have never thought deeply about the issues we raise and are surprised by what they find themselves saying as well!"

20. She added, "At the same time, the doctors who have seen the research results have confirmed that the results successfully describe many of the problems they face and what medical practice in Singapore is like in the care of patients at the end of life. The doctors also tell us that these issues are important to share with the public and to raise with policymakers."

~oOo~

About the Lien Foundation

The Lien Foundation is a Singapore philanthropic house noted for its model of radical philanthropy. It invests in innovative solutions, convenes strategic partnerships and catalyses action on social and environmental challenges. The Foundation drives institutional capacity building to address crucial community needs, and empowers individuals to reach their full potential. It seeks to enhance educational opportunities for the disadvantaged, excellence in eldercare and environmental sustainability in water and sanitation.

The Foundation advocates better care of the dying as part of its mission to advance eldercare. It first conceived and spearheaded a "Life Before Death" initiative in 2006 to create greater public awareness about end-of-life issues in Singapore. Since then, the Foundation has continued its drive to highlight the urgent need for improved care for the dying. It also sought to de-stigmatise death and dying by spurring 'die-logues' amongst the public. In 2010, the Foundation commissioned the Economist Intelligence Unit to conduct the first-ever global Quality of Death index ranking 40 countries on their provision of end-of-life care. In June 2011, the Foundation released a consultative study based on the perspectives of 30 leaders about how to improve care for the dying in Singapore.

www.lienfoundation.org

Media Contact: Genevieve Kuek Qeren Communications Tel: +6597633110 gen@qeren.biz