

SMA NEWS



Volume 44 No. 2 February 2012

MICA (P) 019/02/2012



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Dr Jacqueline Chin and Dr Jacinta Tan

The study, “What Doctors Say about Care of the Dying”, was commissioned by the Lien Foundation and conducted by Dr Chin and Dr Tan. Their study focuses on an issue of growing importance in Singapore’s ageing population – medical care for the dying. The two researchers interviewed Singaporean doctors who are practising in a wide variety of situations and providing care to the dying. Their study discusses important issues such as what the “end of life” is and when it starts, the needs of patients’ families, the role of finances, when and how to cease treatment, and how the medical system in Singapore affects the medical care delivered.

Dr Chin and Dr Tan wrote the following article to provide introductory insight into their research. You can access the original study at <http://www.centres.sg/node/105>.

Let’s say, “The richness of maturity of the society can be measured by how much it puts into the care of those who are in need, the disabled, the dying”. And as we grow as a society, if you find we have less and less time and interest in those who are disabled and dying, we may not be really growing as a society. We may be growing as a body of entrepreneurs, or moneymakers or survivors.

– Doctor 01

In recent years, there has been an increasing recognition of, and interest in, the end-of-life phase of life. The medical specialty of palliative care has developed along with the provision of hospices and hospice home care for patients near the end of life in Singapore. At the same time, there has been some public debate about related issues – the improvement of healthcare leading to more chronic courses of illnesses; the ageing population and the increasing burden of caring for the elderly. Some patients have demanded, and two local legal scholars suggested, changes in the law to allow provision of euthanasia and physician-assisted suicide. All these raise practical and ethical questions which need to be answered if healthcare provision in Singapore is to remain relevant and appropriate to

the needs of the population.

There is very little evidence to guide the development of policy and practice of care of patients at the end of life in a modern Asian country like Singapore. Most of the research at the end of life comes from countries in Northern Europe, North America, and Australasia, which have different cultural and philosophical traditions that underpin their current medical, ethical and legal practice. Given that end-of-life issues involve many value-based and culture-based factors, it is likely that these research results do not apply well to the Singapore context, and it is not clear what the differences may be.

Although many different healthcare professionals deliver end-of-life care, doctors still have primary responsibility for most major healthcare decisions at the end of life in Singapore. For this reason, we decided to focus on doctors for a qualitative research interview study. We recruited 78 doctors from a wide range of disciplines and work settings. Interviews were flexible, covering certain areas but also exploring the doctors’ own accounts and experiences.

We found that doctors in Singapore have wide ranging views about what constitutes “end-of-life”. The difficulty of settling on a single biological, existential or operational definition indicates the diversity of needs and goals that must be addressed in end-

of-life care provision. Doctors see themselves as having the responsibility for deciding when medical science is no longer going to help patients recover; responsibility for signalling when the goal of care should shift from recovery and cure to comfort and quality of life; and responsibility for guiding patients to accept the shift of goals and to prepare for the end of life.

... I'm aware there are different definitions but to me if you can more or less predict the lifespan of a person to be six months to a year I think that will be about time to start thinking "Is this the end of life for this person?" Of course the challenge is always, is this prediction accurate? Sometimes we do better than other times. The other way of looking at it is really if there is, even if it's not really near end of life with definition of up to six months to a year, but I think if the aim of helping the person is no longer purely curative or making the person better. But really looking at how the person can continue to preserve as much of the functions as he or she can and at the same time maintain the dignity of life and the quality of life to any extent possible, then I think you can also consider the expertise of an end of life care person. Whether in terms of the different domain of health, whether it's the physical, emotional, spiritual, so that this person can also enjoy that quality of life in different domains. And the time I sometimes feel is no longer as crucial.

– Doctor 59

Doctors told us that the religious beliefs of patients and their families, as well as Singapore societal attitudes affect how well preparing patients for death is achieved. Some religious and ethnic communities are better able to face death, while others find it a taboo subject to be avoided. It emerged from the interviews that the principle of patient autonomy, well accepted in developed Western countries, is hard to apply in Singaporean family culture. Decision making in Singapore tends to be made collectively by families, sometimes without the patients being given information about their diagnosis or involved in healthcare decisions. One of the most difficult ethical issues doctors face is collusion with families in deceiving patients. They often need to work hard with family members to be allowed to talk to patients truthfully. Some patterns of family decision making were of concern. Elderly patients and legal minors are often passive in decision making or protective of their families, with the result that doctors often find it difficult to discern their true wishes.

I think that when you practise in the West, you take it for granted that everyone is very autonomous, the right to self-determination is a very important ethic in the West. Here, decisions are being made as a family. And I think that here, 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, which site – is it in the hospital? In the hospice? In the home? 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.

– Doctor 62

It is sometimes difficult for doctors to make "best interest" decisions where individuals see themselves and their interests as intertwined with others in the family. In some cases, patients make altruistic sacrifices for the sake of the family; in others, families insist that a patient's interests do not take precedence over other more pressing family needs. Doctors said that the quality of filial piety as a value affirmed in Singapore society is strained by the heavy personal burden of healthcare finance upon the "sandwiched generation" of persons who have responsibility for their elderly parents and their children.

The Singapore healthcare system is complex and works well for certain models of illness, but the general set up and financial system may not fit the needs of many patients at the end of life who often have long term and chronic healthcare needs, and require more treatment and support outside the acute hospital system. There tends to be a lack of coordination for individuals and their families as they move from one type of care to another, or one institution to another. Doctors talked about how the current healthcare system does not support patient wishes to die at home. This is because of the lack of financial, social and physical support for this option, including lack of consideration of the burden to informal caregivers and logistical problems in certifying death at home. The doctors identified a need to debate the healthcare system openly in order to develop new ideas and policies about better access to good healthcare and holistic, seamless and appropriate care for patients and families whose needs will vary and fluctuate at the end of life.



Given the recent controversy over the issue of euthanasia and physician-assisted suicide, we specifically asked doctors for their views. Almost all doctors we spoke to do not want their profession to have any part in such acts, though many specific cases of severe suffering do trouble a few. Doctors see very distinct moral differences between withholding and withdrawing treatment, and hastening death – while both withholding and withdrawing treatment are morally acceptable to most, hastening death is morally unacceptable to almost all. Withholding and withdrawing treatment are seen as morally acceptable in cases of futility of treatment or competent patient refusal, but withholding and withdrawing nutrition and hydration are much more ambivalently viewed, because feeding carries an emotional significance to both doctors and families.

We hope this research will educate, inform and stimulate debate amongst doctors, the public, policymakers and lawmakers about the issues surrounding the medical care of patients at the end of life. We also hope that this is the start of a new way of engaging healthcare professionals, patients and their families with medical ethics. You can download our public report from <http://www.centres.sg/node/105>. **SMA**

Thoughts to share? Email news@sma.org.sg.



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Dr Jacinta Tan has a multidisciplinary background of medicine, child health, philosophy and psychology, and sociology. She is a fully qualified child and adolescent psychiatrist who is also a medical ethicist and empirical ethics researcher. She is a Senior Research Fellow at Swansea University, Wales, and was also a Visiting Senior Research Fellow at the Centre for Biomedical Ethics, NUS. She specialises in empirical ethics research using sociological methods.