

What Doctors Say About

# CARE OF THE DYING



*A study commissioned by*



Jacinta OA Tan & Jacqueline JL Chin

*With contributions from*

Terry SH Kaan & Tracey E Chan



What Doctors Say About

CARE OF THE DYING

Jacinta OA Tan & Jacqueline JL Chin

*With contributions from*

Terry SH Kaan & Tracey E Chan

Copyright © 2011 Jacinta OA Tan, Jacqueline JL Chin,  
Terry SH Kaan and Tracey E Chan

Published by The Lien Foundation  
1 Raffles Place  
#51-00 One Raffles Place  
Singapore 048616

Cover Image: Citizen of the Empire Clerk, 91.5x76cms/ 36x30 inches, oils on canvas, 2003  
Image in Chapter 1: Trace, I installation with 18 drawings, table, light bulb, 2007  
Image in Chapter 2: Ephemera, variable dimensions, paper and lightbox, 2010  
Image in Chapter 3: Down the Kampong Lane, 76x56 cms/ 30x22 inches, oils on canvas, 1991  
Image in Chapter 4: Anthropological Study of a Nation, 40.6x40.6cms, soft pastels, collage,  
drawings, 2005  
Above images used with permission by Susie Wong. © Susie Wong

Designed and produced by  
ARMOUR Publishing Pte Ltd  
Kent Ridge Post Office  
P. O. Box 1193, Singapore 911107  
Email: mail@armourpublishing.com  
Website: www.armourpublishing.com

15	14	13	12	11
5	4	3	2	1

All rights reserved.

No part of this publication may be reproduced, stored in a retrieval system or transmitted,  
in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without  
the prior permission of the copyright owner.

Printed in Singapore

ISBN 13: 978-981-08-9830-4 (Paperback edition)  
ISBN 13: 978-981-08-9831-1 (Digitised version)

#### **National Library Board, Singapore Cataloguing-in-Publication Data**

Tan, Jacinta, 1965-

What doctors say about care of the dying / Jacinta O.A. Tan & Jacqueline J.L. Chin with  
contributions from Terry S.H. Kaan & Tracey E. Chan. – Singapore : The Lien Foundation, c2011.  
p. cm.  
ISBN : 978-981-08-9830-4 (pbk.)

1. Physicians – Singapore – Attitudes. 2. Terminal care – Singapore – Public opinion. 3. Medical  
ethics – Singapore – Public opinion. 4. Public opinion – Singapore. I. Chin, Jacqueline J. L., 1967-  
II. Title.

# CONTENTS



<i>iv</i>	<b>Acknowledgements</b>
<i>v</i>	<b>Foreword</b>
<i>vi</i>	<b>Executive Summary</b>
<i>viii</i>	<b>Introduction</b>
<i>2</i>	<b>Chapter 1</b> The End of Life: Diverse Concepts, New Significance
<i>12</i>	<b>Chapter 2</b> The Role of the Family
<i>28</i>	<b>Chapter 3</b> Healthcare for the Dying in Singapore
<i>36</i>	<b>Chapter 4</b> Law and the End of Life
<i>50</i>	<b>Conclusion</b>
<i>51</i>	<b>Endnotes</b>
<i>53</i>	<b>Resources</b>
<i>54</i>	<b>Appendix</b> Research Team and Methods

# ACKNOWLEDGEMENTS



**T**he authors wish to thank Associate Professor Terry Kaan and Assistant Professor Tracey Evans Chan for their contributions to the development of the whole project and specifically for co-writing the chapter on law. Our distinguished steering group has also given generously of their time and expertise, and we would like to thank: Dr Noreen Chan, Associate Professor Dr Chin Jing Jih, Associate Professor Dr Cynthia Goh, Associate Professor Dr Goh Lee Gan, Professor Desley Hegney, Dr Tan Yew Seng, Dr T Thirumoorthy, Dr Major Tor Phern Chern and Dr Wu Huei Yaw. We would also like to thank Mr Lee Poh Wah and Mr Gabriel Lim of the Lien Foundation for their unstinting and enthusiastic support of this research, and Ms Genevieve Kuek for her helpful advice. Dr Dixie Tan and Dr Grace Tan provided tireless and invaluable assistance with proofing and editing, Ms Iris Wee, Ms Rosnizah binte Mohammed Ali, and Mr Alden Chng gave us kind administrative support, and Ms Luo Zhifei put in many hours of hard work on project administration, coding and analysis, for which we are deeply grateful. We thank Mr Calvin Ho and Ms Syahirah binte Abdul Karim for their help with the workshop we conducted at the National University of Singapore on 9th July, 2011, and the 21 healthcare professionals including 2 observers in attendance who participated in the validation of this research. Finally, and most importantly, we owe an enormous debt to the 78 doctors who generously gave of their time, experience and selves in this research enterprise.

# FOREWORD



In 2010, Lien Foundation, the Singapore philanthropic house behind the “Life Before Death” initiative, commissioned researchers based in the Centre for Biomedical Ethics at the National University of Singapore to carry out a study of the views and attitudes of doctors in Singapore towards the care of patients at the end of life. This is the first empirical ethics research project that has been undertaken by the Centre for Biomedical Ethics in the National University of Singapore, and it has been an exciting journey for all involved. This report is a brief account of the research results, and further, more detailed academic publications will follow. This lay report is intended to 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 hope that this is the start of a new way of engaging healthcare professionals, patients and their families with medical ethics. It would be hard to imagine a more relevant topic for public understanding and debate than this one, which will affect us all in one way or another throughout our lives. The two principal researchers, Dr Jacqueline Chin and Dr Jacinta Tan, are to be commended for carrying out such a well-designed, thorough and highly topical study.



**Professor Alastair Vincent Campbell**  
*Chen Su Lan Professor of Medical Ethics  
Director, The Centre for Biomedical Ethics  
National University of Singapore*

# EXECUTIVE SUMMARY

“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)

## Chapter 1 The Concept of the End of Life and its Significance

- 1 Doctors in Singapore have wide ranging views about what constitutes the end-of-life as a phase. The difficulty of settling on one meaning, whether biological, existential or operational indicates the diversity of needs and goals that must be addressed in end of life care provision.
- 2 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.
- 3 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. Better understanding of how patients approach and make sense of death and dying through their culture and religion helps doctors meet the care needs of patients at the end of life.

## Chapter 2 The Role of the Family

- 4 The principle of patient autonomy, well accepted in Western developed countries<sup>1</sup>, is generally difficult to apply in Singaporean family culture. Decision making tends to be made collectively by families, and doctors said that this can interfere 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 collusion with families in withholding the truth of diagnosis from patients. They often need to work hard on persuading family members to be allowed to talk to patients truthfully.
- 5 Some patterns of family decision making were of concern. Elderly patients and legal minors were often passive in decision-making or protective of their families, with the result that doctors often felt it was difficult to discern their true wishes.
- 6 It is sometimes difficult for doctors to make ‘best interests’ 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 the patient’s interests do not take precedence over other more pressing family needs.
- 7 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



‘sandwich generation’ of persons who have responsibility for their elderly parents and their children.

### **Chapter 3**

#### **Care of the Dying within the Singapore Healthcare System**

- 8 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. They 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.
- 9 Doctors talked about how the current healthcare system does not support patient wishes to die at home, because of the lack of financial, social and physical support for this, including a lack of consideration of the burden to informal caregivers, as well as logistical problems in certifying death at home.
- 10 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 wholistic, seamless and appropriate care for patients and

families whose needs will vary and fluctuate at the end of life.

### **Chapter 4**

#### **The Law and the End of Life**

- 11 The law is generally seen by doctors as setting the boundaries for, rather than dictating, their clinical practice. They do not seem to notice discrepancies between their clinical practice and Singapore law that governs adult patient consent and confidentiality.
- 12 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 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.
- 13 Euthanasia and physician-assisted suicide are largely disapproved of, and most doctors do not want their profession to have any part in such acts, though many specific cases of severe suffering do trouble doctors.

# INTRODUCTION

## The Project

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 several related issues—the improvement of healthcare leading to more chronic courses of illnesses that would previously have caused people to die quickly; the aging population and the increasing burden of caring for elderly people who would have chronic illnesses; and the demands of some patients for 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.

It has become evident that there is very little evidence to guide the development of policy and practice of care of patients at the end of life. Most of the research at the end of life comes from First World, fully-industrialised countries in Europe, the United States and Canada, and Australasia. 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 between Singapore, which has a very modern, advanced healthcare system in an Asian context, and these countries. This project aims to provide preliminary research evidence of end-of-life issues in the Singapore context, which can be built upon in future research and project initiatives.

---

## What We Did

Although there are many different healthcare professionals involved in care of the dying, doctors still have primary responsibility for most healthcare decisions at the end of life in Singapore. For this reason, we decided to focus only on doctors for this study. Some doctors are very experienced and highly skilled in managing problems that patients and their families face at the end of life; other doctors rarely see dying patients and may be poorly equipped to help such patients when they do meet them. In order to examine the range of doctors that patients may meet at the end of life, we decided to interview as many types of doctors as we could. The questions used in the research were developed with the assistance of a distinguished steering group of experts.

We used a qualitative interview method, which means that the interviewers talked to the doctors in a confidential research interview using a flexible method of dialogue which covers all the areas named in a Topic Guide but also follows the doctors' own accounts and experiences. Please see the Appendix for a more detailed account of the research method. Seventy-eight doctors were recruited from a wide range of disciplines. They also came from a wide range of work settings: private family medicine, polyclinics, private medical home care, community hospitals, hospices, private specialist practice, restructured hospital specialist practice and academic medicine.<sup>1</sup>

---



# 1

## THE END OF LIFE DIVERSE CONCEPTS, NEW SIGNIFICANCE

“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)

### 1.1 The definition of ‘end-of-life’

It is now quite common amongst doctors to talk about ‘end-of-life’. There is even a medical specialty, palliative care, that (amongst other things) focuses on medical and other needs of patients at the end of life. But what do doctors think ‘end-of-life’ is? We asked doctors what the term ‘end-of-life’ means to them, and we found that in spite of being a commonly accepted term, trying to pin down what constitutes ‘end-of-life’ is not straightforward. The term ‘end-of-life’, it turned out, means a lot of different things to different people, and even different things to the same person.

#### ■ Biological and functional definitions of ‘end-of-life’

There were some who thought that ‘end-of-life’ simply meant death, nothing more or less; or that ‘end-of-life’ was perhaps a person’s last few hours or days alive, when that person was literally in the process of dying. For example, most doctors use the

cessation of heartbeat and breathing as the markers of death in ordinary clinical practice; but in the formal legal sense, diagnosis of death was actually made using specific criteria for brain death, as is done when organs are going to be used for transplant.

“[It is] the physical end of life. So death means, physically, there’s no longer someone ... able to function as a living organism. Whatever defines a physical organism. That, to me, is end-of-life, and that is equivalent to death.” (Doctor 02)

#### ■ Broader definitions of ‘end-of-life’

Most, however, saw ‘end-of-life’ as a bigger, longer and more complex stage in life. In medicine, doctors explained, there were broad definitions about ‘end-of-life’ being a distinct stage in medical care.

“[T]o me, ‘end-of-life’ is really the time from when it becomes certain, whatever disease process he may have, it’s no longer reversible. And then from this point onwards, it is a march, a progression towards death. And to me, that’s end-of-life, and end-of-life care.” (Doctor 01)

“From a clinical point of view, I would say that when, seemingly, the treatment goals have shifted from cure ... you know, to that of maintaining comfort, and that the prognosis in terms of actually reversing the disease process has ceased, and we’re looking now at comfort and end-of-life type of treatments. It’s defined more like the goals of treatment.” (Doctor 13)

“For me, I refer to the illness, for example, if the illness itself is going to be progressive, and is going to get worse with time. So that is how I define my life-limiting illness as ... not so much by the age, as by the illness. For example, dementia itself can be a life limiting illness, because it is going to progress.” (Doctor 63)

### ■ Policy and operational definitions

There were also much narrower operational criteria which were used for practical purposes, but which fail to accommodate these broader definitions. An example of narrow criteria is the clear-cut, time-based definitions of end-of-life which are currently used to determine when patients become eligible to have their hospice care paid for by the government. However, doctors pointed out that medical science is still poor at determining exactly how long an individual person has left to live, so this can be a problem. For example, there have been difficult cases where patients who were given less than six months to live go to a hospice but then had to leave because they had outlived their allocated funding for hospice care.

“The way [the] Singapore Government funds, end-of-life will translate into the last three months. At the most, six months, because the Singapore government funds every Singaporean citizen up to six months to give them time to come to terms with it, granting palliative care provision for up to six months of each individual's life. So if you've used it up before you die, too bad, you don't get it again. ...It's definitely very difficult, we are very bad at [prognosticating], we over-estimate all the time. From a hospice point of view, it's three to six months. From a home care hospice point of view, it's one year because the funding for them is one year. That's the practical way of defining [the end-of-life phase] for service delivery.” (Doctor 03)

Other doctors challenged the priorities of end-of-life debates, and the need for a hard definition of the end of life, preferring the language of ‘goals of care’, and the needs of the dying.

“So maybe we shouldn't worry too much about the word. So I don't think the term end-of-life should be given priority. We

shouldn't be too obsessed with the term end-of-life. Maybe we should be more obsessed with needs or a better term for it, or goals of care. Yes, we should be more obsessed with goals of care and needs than on end-of-life. Because that boxes people in.” (Doctor 01)

Several doctors thought that the end of life was when patients were not expected to live more than a certain period of time, usually counted in months up to one or two years. Most doctors felt that the end-of-life stage is much more ill-defined and poorly captured by time-based criteria, because to them it is when patients suffer from what they called ‘life-limiting illness’. A life-limiting illness is one which is incurable and likely to end the life of a patient prematurely, but nevertheless death may not occur for many more years. A good example of a life-limiting illness would be neuromuscular dystrophy, where the patient progressively loses the use of his or her muscles and eventually is unable to breathe.

### ■ The ‘surprise question’

How then, do we even know when a person is in the end-of-life stage? Some doctors suggested that the litmus test could be a hypothetical question of whether the doctor would be surprised if a particular patient died soon. If asked that question and a doctor said, no, they would not be surprised, then the patient probably is at the end of life—irrespective of how it might be defined.

“End-of-life would be when the end is near but not so, so near. So maybe within a year if the child were to pass away, I would not be surprised.” (Doctor 41)

“And I think at least from my point of view, it's important to consider these people, maybe not obviously at the end of life, but who could be nearing the end of life

because when things do happen, they, their physicians, and their families all turn around and say, “Oh, but it was so sudden!” But then actually when you look back, it wasn’t really that surprising. The end may have come very quickly but it wasn’t that surprising, in the bigger scheme of things.” (Doctor 05)

### ■ Spiritual and other non-medical understandings of end of life

Finally, many doctors said that end of life was not just a medical issue, but a spiritual, emotional and psychological stage.

“[I]nternally, for oneself, at certain stages of meditation, you’re supposed to meditate on how rebirth occurs. Why [the] law of karma works, and how is there causes and conditions, and how it impacts on the new rebirth. And subsequently, experience of this life—how is it [the law of karma] linked with experiences of that life and the past, previous life. So you have to analyse those [matters] deeply. That’s when you have to analyse in yourself: how did the death happen in you, in the past life? And how did the rebirth occur in your life? So, spiritually, that is how I understand death to be; but clinically I can’t do that because, unless one has psychic power, we can’t tell. So we go by physical, objective signs.” (Doctor 09)

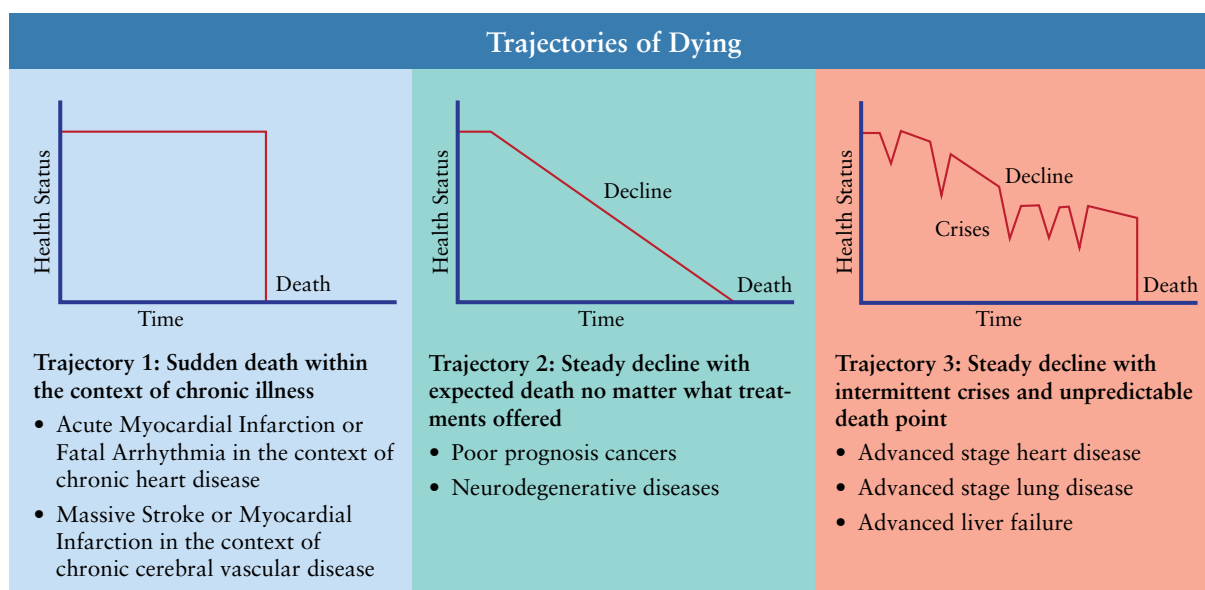
“The Muslims view death as the end of the life in this world. Because Muslims believe in the hereafter. The world is a transient place where you sow, you work, where you try to do as many good deeds. And it’s a transient thing. As you pass on you will go on to another life, basically. So death is just a point to deliberate between the life in this world and the life in that world. So that’s how Muslims view death.” (Doctor 76)

“When people roughly know when they’re going to die. They plan what they want to do with the rest of it [their life].” (Doctor 07)

## 1.2 How ‘end-of-life’ affects decisions

### ■ Balancing curative treatment and comfort care

For some doctors, the end-of-life stage marked a distinct phase where the goal of treatment shifts from ‘cure’ to ‘comfort care’. Comfort care, as they described it, consists of treatment and care with the aim of maximising quality of the patient’s remaining life, rather than strenuously trying to maximise the quantity of remaining life. The important difference is



Source: Glaser and Strauss ([www.fammed.washington.edu](http://www.fammed.washington.edu))



that treatment with the goal of cure, which tries to help the patient survive longer, usually means a great deal of discomfort in the short term. In other words, aiming for cure often involved a lot of short term pain and discomfort with the aim of gaining a lot in the long term in terms of added years of life; but aiming for comfort involves trying to maximise current conditions and quality of life because there is no prospect of gain in the long term because of the inevitability of death.

“For example, insulin. Insulin treatments to a patient may not seem fun. It’s an injection. But physicians all over the world argue, and I guess that’s how I’ve been trained as well, that it’s just a shot, it isn’t that painful and you get used to it. But you know, if you are able to control your diabetes well, you are going to prevent this, prevent that, and you are going to live much longer—and so we push the patients into doing those things.”

**Interviewer:** Whereas when it’s terminal you may think ...

“That’s right. Then the reverse would have taken predominance, and then the quality of life will be the predominant consideration, rather than actually being based on longevity.” (Doctor 02)

### ■ Mortal risks

An unusual idea was that patients could be in an end-of-life stage while the goals of treatment were still to cure the patient. The doctor who suggested this explained that some of her patients had such serious illnesses that they had to be guided to face up to the strong possibility of imminent death, in particular, death due to the consequences of treatment itself; but that, at the same time, the treatment was not futile but trying to cure the patient.

“[Y]ou know that there is this upfront 20% mortality in any [names major medical procedure]. And if you’re going

for a procedure that has got [an] upfront mortality rate of 20%, you had better prepare in case you don’t make it through. So that’s how we perceive it. So, I’d say that the challenge is how to prepare for end-of-life issues, while giving hope for a cure and fighting to survive. Does that make sense to you?” (Doctor 14)

## 1.3 The role of the doctor in the end-of-life stage

### ■ The doctor as leader in the care team

Many doctors also felt that deciding that the end-of-life stage had been reached is one of the jobs a doctor has. This is because he is in a position to judge, based on his medical expertise, when further medical treatment aiming for cure or recovery is futile. In other words, in a world of increasingly sophisticated medical technology and increasing expectations on the part of patients and their families of what that medical technology can do for them, the doctor is the one who may have the painful task of telling patients that medical science cannot do any more to heal them. At this point, the doctor has the further task to guide the patient and his or her family to accept the inevitability of an imminent death, and to prepare for this.

“[T]he stage before that, when you’re not sure, or you’re battling, for instance, and you know that you may be going this or you may be going that way, you are not quite sure. To me, that is not yet end-of-life because, at that point of time. During end-of-life care, the physician’s goals have changed. Before end-of-life care, the physician is still preserving [life], to prevent death. But at the point when the physician now determines to his best professional wisdom, “my goal now is no longer...I’m no longer able to achieve my previous goals, I now have to go toward this goal:

to have this person, and everybody that is involved, to prepare for the demise of the specific person". That's when it's end-of-life care. And the physician has to clearly signal this change of goals: documentary-wise, team-wise, everybody, to decide. ...Of course it's not easy for the physician to take the decision. And physicians need to learn how to come to that decision. What is the process, how you do it. That's the difficulty in real life: its complexity, its uncertainty, how you deal with and judge certain things.

” (Doctor 01)

### ■ Doctor in the gap

Several doctors talked about taking on roles that are not strictly medical when dealing with people who are at the end-of-life. Some of this was due to the lack of other resources or specifically trained professionals who could help such patients with psychological, spiritual and social needs. Doctors, however, often felt that it was their role to not only deal with their patients' medical needs, but also to treat their patients more holistically by addressing the complexity of all their other needs.

” [T]hey were told by the hospital that she's ninety plus, this is a sacral sore, she's septic. Just take her home. Let her die, you know? And then the GP was looking after her for ages. He was my friend who called me up and said, "Do you think you want to see her? Because you do wounds, right?" I do. So I went to her house. The family was very nice. They were so supportive. They got a hospital bed that could be, you know, cranked up and down. They have a maid to look after her and they were doing these dressings all wrong. So I was, like okay, they're very hardworking about it but they're not doing it right. And they were always feeding her white porridge, so she had basically not much nutrition. So I went to the kitchen, I inspected it. I taught the maid how to cook. Like, you know, what kind of soup, how you puree stuff so that

she has something to let the flesh grow. And then you use [a type of dressing] to start dressing. Taught her how to clean, be neat, and then I made another visit, to make sure that she got it right. And the flesh just grows all the way back and she only died one year later instead of a couple of weeks. ” (Doctor 07)

### ■ Facilitator of the dying patient's aims

Some doctors said that they could not just abandon their patients after drawing a line for medical interventions, and there was a strong theme of the role of doctors being to care for their patients, to listen to them, and not just to cure them. This is not to say that there are no medical needs at the end-of-life. Doctors talked in particular about the need for relief of pain and of other symptoms of the illness at the end-of-life, and felt that medicine still has a big role to play in helping people to be comfortable, fulfil wishes and to be able to have a 'good death'.

” ... we already counselled her [patient] and told her it's [the procedure she asked for] not curative. I mean, it's way against principles but it wasn't impossible because it is something that you can do. But you've got to get the patient to understand that we're only doing this for you because you asked for it. But given a choice we would remove the whole thing. But anyway she said she just wanted to be happy. So we just did it for her. ” (Doctor 07)

” I think most people associate end of life with palliative care, and most people associate palliative care with oncology. And I think that's a very skewed or very restricted, restrictive view of what palliative care is. You can have non-oncological palliative care, end-stage renal failure. You can have liver disease, end-stage hepatic disease. All these are palliative. So I think it's a transition, it's that journey I think, in the last few weeks



before you breathe your last breath. That's end-of-life. So if you ask me, end-of-life care ... it applies to everyone who comes to us, or transits home, to die. That to me is end-of-life care. So it's not so much, sometimes ... by the time you reach the end, it's not so much medical. It's psychological, spiritual. It's handling family dynamics. It is ensuring that the patient can—[2 second pause] has the autonomy to decide what he wants, to say how he wants to go. A lot of times they want an extension not because they are afraid to die, but they want an extension to finish all unfinished business. "I just want to live long enough to wait for somebody to say goodbye to me." And then that's it. It's good enough. ” (Doctor 19)

#### 1.4 Religious influences at the end of life

Religion greatly affects how patients respond to the end of life. The doctors spoke of how having a religion changes the meaning of the end of life for their patients. They also described how religion affects the way that patients deal with facing the issues of end-of-life.

##### ■ Traditional Chinese beliefs about death

A large number of patients and their families in Singapore call themselves 'Buddhist' or 'Taoist' but are not strictly or solely following the teachings of Buddha or Lao Tzu. Instead, they hold traditional Chinese beliefs in an assortment of gods and spirits and follow many traditions concerning death and dying. The doctors described these Chinese as having a strong taboo of speaking of death or associating with death, for example having a person die in the home or being physically near someone who is dying, or being breathed upon during a person's last breath. They explained that this makes the notion of bringing a patient home to die amongst his

or her loved ones in familiar surroundings, something considered self-evidently good in many cultures and developed countries, a problem for these Chinese. Superstition around the subject of death was also a problem, for example, to mention death is to invite it or would be bad luck. This makes bringing up and discussing the subject of death and dying very difficult with these patients and their families. This means that important issues and decisions tend to be overlooked, such as the making of wills and preparing for the possibility or eventuality of death, for example making Advance Medical Directives or appointing donees in anticipation of mental incapacity.

“ [W]hen the people die, the way that the Taoist [Speaker means here a syncretic version of Chinese religions practised in Singapore] reacts is, "Oh no, they have died and you must then do all sorts of things to pacify the “牛头马面” [Mandarin, literal translation: Bull Head, Horse Face; two guardians of the Underworld in Chinese mythology] and then they will burn... all these things, and then have all these rituals that they must follow, and all these taboos, thousand and one of them. Like, you know, if you get married, you cannot have a death near [the date]. ...If you have a new baby, [and] you have visited a grave, you cannot go near it [the baby]. If you have just given birth, you should not attend somebody's wedding, and obviously, they are not going to attend anything that has to do with death. ” (Doctor 68)

“ Because our old people had been through the Japanese War. They had seen coffins sticking out of the ground. But after that we became very hush-hush. It's something that we understand in our psyche but something we don't say. And it's because it's inauspicious to say. So when I talk about death and dying to a Chinese in Chinese, we would refer to the traditional term which is 百年之后 [Mandarin, literal translation: after

a hundred years, an euphemism for “after you’ve passed away”). I wouldn’t say, “Uncle, 你死了之后 [Mandarin, translation: after you’ve died]”. I would say, “Uncle, 百年之后有什么交代?” [Mandarin, translation: what are your instructions when you’ve reached a hundred years?] It’s the traditional context. And we know our cultural background ...

Interviewer: Ah, this is new. This is important. You can talk about death. But you may use a different way of alluding to it that is acceptable to the other party.

“Right. When the Emperor is dying, and he asks who’s going to succeed him, you back in [to the topic by introducing it indirectly], “百年之后” [Mandarin, translation: after a hundred years].

Interviewer 2: Can you translate that?

“一百年. [Mandarin, translation: a hundred years] If you go back [in time], you can find [this] in [ancient Chinese] references.”

Interviewer: Ah. So it’s quite acceptable to die at a hundred.

“So your life is completed ... what are your plans. In fact I don’t say die very often.”

Interviewer: This is really new and I think it’s actually very, very important. So you might say in Chinese, “百年之后”. Then what else do you say?

“[You might] say: If you’re very sick, when you are not around anymore, are you worried about your children? These are the things that in our local context tell the patient that he may not make it. ” (Doctor 71)

### ■ Muslim and Christian acceptance of death; and people with no settled beliefs

“[L]et’s say a [Muslim] mother loses her child... yes, they will grieve for a while but they tend to be able to overcome it much faster, yeah they will still feel sad and all that, but you can see that they are handling it much better, they seem as [if to think], you know, [that the] person has moved on, that God has taken the person back—similar to how the Christian will see it. ” (Doctor 68)

“ I think, for example, Muslims are very accepting. Normally their families are supportive. They camp in the hospital. The entire kampong [Malay, translation: village]. And they will bring their mats, their picnic stuff, and they’ll be, like, you know, in the stairwells, you know, occupy all the stairs and, you know, just sitting there to accompany the patient in shifts.

Interviewer: Wow.

“You know, one or two, they go in, they see the guy, they help him. So it’s a very good testimony of family togetherness. Chinese, it depends. To me it’s like, I find that for Christians, I think Christians die peacefully. They are not afraid of dying. They know what’s at the other end. Normally those who are very cool about it, they just say bye.”

Interviewer: Oh do they?

“Yeah they do. The ones who don’t believe in anything tend to be more fearful but I need to sit with the dying on their deathbed. Just to sit with them and hold their hand because sometimes you have to hold their hands because nobody visits them. You know, some of them have such dysfunctional families that people don’t visit. And they’re very lonely, no one to talk to. And they just want to talk to you. Because they have nobody. And sometimes they’re like, so upset, and then they know they’re dying and there’s nothing they can do. So with all the tubes and everything just hold their hand. They know when they’re going. Just hold until they let go of you.

Interviewer: Well that’s great that you get to do that.

“Well, yeah, but you know it’s not particularly nice. You see that patient is going to die and, it’s like, and you know there’s nothing much you can do because you’ve done max and you still have to see him go. But they’re lonely you know. They’re scared and, like, that’s all you can do. ” (Doctor 07)

### ■ Buddhist outlook on death

Buddhists were also accepting of death and the end-of-life, but for other reasons.

Devout Buddhists were described as having the ability to meditate to overcome pain, and death was viewed as the gateway to another existence, with the experience to be faced calmly and without emotional attachment to earthly things and relationships.

“Well I’m Buddhist. And as a Buddhist, I am a staunch meditator. ... [W]hen the death consciousness occurs, immediately after that is rebirth-making consciousness. At that point when the death consciousness occurs, that is death. Death consciousness occurs in one billionth of a second. It’s very fast. Death consciousness occurs, and in the last moment, click, and then that’s death.

Interviewer: And then after that, you experience something else?

“That would be a new life.” (Doctor 09)

### ■ Doctors handling their own religious beliefs

For doctors who were themselves religious, whether Christian, Muslim or Buddhist, their beliefs were important to how they deal with patients who are dying, and their families. Doctors, being familiar with death in the course of their work, were much less superstitious about death themselves, and saw it as their vocation to help those who were dying. The doctors who had strong religious beliefs were very careful about being sensitive to their patients’ beliefs and vulnerabilities, and tended to share their own convictions only with patients who were fellow believers.

“[The] government said: ‘Look, the hospital...’ I mean, it’s a fact, ‘The hospital is not the place for you to promote your faith, to evangelize.’ Because of that, medical staff are sometimes reluctant to raise spiritual issues. I should be able to talk to the dying patients or the relatives about spiritual issues without having to evangelize. But of course if I’m a Christian and my patient is a Buddhist, I’m supposed to know something

about [the] Buddhist concept of death. And if I don’t know, society expects me to find a doctor who knows the Buddhist things, who can then facilitate it.” (Doctor 01)

The doctors’ own religious beliefs also affected how they viewed moral issues such as euthanasia, and this will be discussed later.

## 1.5 Societal attitudes to the end of life

Singaporean societal attitudes have a major impact on how doctors treat patients at the end-of-life.

Several doctors described Singaporeans as suspicious people, who might think that a doctor was giving up on them if he or she spoke of accepting the end-of-life or advised against continued treatment.

Furthermore, doctors described that Singaporean families find it difficult to suggest to their relatives that they should do advance planning for death such as writing wills and stating wishes concerning terminal care, because ill relatives would accuse them of wishing them dead or wanting their property. Finally, there were accounts that some people think that the encouragement of patients to be able to go home in order to die in familiar surroundings amongst those they love is an attempt on the part of institutions and the state to save money at their expense. This account from doctors suggested that society itself is still distrustful of the motives of families, healthcare professionals and the government, which affects issues concerning death and dying.

### ■ Why families tend to avoid end-of-life conversations

“I think people don’t want to talk about it, number one. It’s because—well my theory anyway—for the children especially, when you talk about it there is also the issue about finance, property, who gets it when

you're gone. It's really bad. Because if you remember in Singapore, [for] the average Singaporean, most, even the lower income, will have property. It's that HDB flat, that little nest egg. So when you talk about end-of-life, immediately the response is, "So you're talking about money." Which, actually, a lot of times, the children, or the other people who are staying with them, don't intend to [talk about money]. They just want to know how you're going to settle your affairs. So it's very coloured with that. So that's number one. Number two is that, well, there's the Chinese father saying, *suay* [Hokkien, translation: unlucky, inauspicious], that kind of thing, don't invite trouble, don't talk about it kind of thing. So that one is also there. Number three is that health literacy is actually very low in this country compared to other countries. ””

(Doctor 06)

### ■ A 'low-trust society'

“I think there are quite a few things here. Singapore is a low trust society and people are very suspicious. I don't know if you've seen that video of the guy in the HOTA [Human Organ Transplant Act] case? The guy in [names hospital] where the mother was pleading with them not to harvest his organs. It's actually on YouTube.”

Interviewer: It is?

“Yes, it is. In fact this guy had intracerebral haemorrhage. They invoked HOTA and were

trying to harvest his organs. And his family hadn't quite come to grips with it yet. And the mother went on her knees, and was dragging, sort of holding, the legs of the surgeon as he was going into the operating room. They handled it very badly. Channel 8 was there. They filmed it and it's got on YouTube. So HOTA is fraught with [does not finish thought]... and when you go on the internet, it's fraught with lack of trust, and suspicion over what's happening. “Have their organs been harvested for wealthy people who can afford transplants?” So similarly here, at the end of life, [the people suspect] the government is trying to save money by not treating their relatives who have expensive end-of-life needs, who need expensive therapies. ”” (Doctor 60)

### ■ Family involvement at the end of life

Singapore family members were described as still very involved in each other's care; and that within the nuclear families at least, there were strong relationships and interdependence. Malays in particular were described as having strong family and community bonds, with many relatives and friends showing up to visit patients in hospital and being very willing to provide support for the ill person, including financial help as required. The issue of family will be discussed in the next Chapter.

---

## Summary

Doctors in Singapore do not seem to have a very clear and settled notion of what constitutes the end of life as a phase. Nonetheless, they see their role as caring for their patients at the end of life even when cure is not possible. 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. The cultural and religious beliefs of patients and their families as well as Singapore societal attitudes, however, do affect how well these tasks are achieved.

---





# 2

## THE ROLE OF THE FAMILY

“Some patients would say, “Oh, the surgeon told me I have a growth here which is quite common, and he wants to take it out.” And I’d ask them, “Oh, so will taking it out make it much better for you, all over again?” And some of them would say, “Yeah, yeah. That’s what he said.” And some of them say, “I don’t know. He said I have a growth and I must take it out, so I take it out loh!” And then they sign consent, and they are all respectful, all gullible, respectful of the doctor’s decisions. And then I’d try to understand what the patient values, what they work as, what their occupation is, and so forth. Then I would try to get the patient out of the room, using some excuses like, “Oh, you need to go sit in a room, get a blood test done.” Then I’d bring the family in and say, “What’s going on here? Tell me about it,” and let them tell their story, and understand their perspective. Because the family needs to feel I am on their side as well. But I have to keep remembering that I am the advocate of the patient. My duty of care is to the patient first, my duty of care to the family [is] second. I have [a] duty of care to both, but the patient is first. But if the patient is so linked in to the family, I have to be very cautious how I do this. So, it gets very difficult sometimes. So I try to listen to the family’s point of view; listen to, try to understand the patient, and then try to see if we can marry the two. Because ultimately the duty of care is still to the patient and what is in the interests of the patient.” (Doctor 03)

### 2.1 The discrepancy between Singapore law and medical practice

One of the strongest themes emerging from the research was the role of the family in decision-making at the end of life. Doctors all described the families of most ill patients at the end of life as being extremely involved in the decision-making process in many ways.

#### ■ Autonomy principle is hard to apply in Asian family culture

Singapore law assumes an ‘individual autonomy’ model of making decisions for patients who have not lost their abilities to make decisions. This assumption is also present in English law as well as the law in most developed countries. The law holds that the individual adult patient has the right to be given information about their medical condition first in a confidential setting, and that they can then make informed treatment decisions with their doctor, including decisions about how much they allow the doctor to tell their family members and how much they wish to involve them in decisions about their care. Most doctors felt that this model of making decisions does not reflect medical practice in Singapore at all.

“It’s very difficult in Singapore. Especially when you have your Western concept of autonomy and all that. It’s really very, very hard to apply. I think doctors try to apply it but I must say we bend the rules; we try to work round it, sometimes, to be creative. Because the truth is: Asians do see themselves as part of a unit. There was a complaint against a particular oncologist where a lady said, “How could he tell our mother without first telling us?” I told her that the oncologist in question had worked in America where they are required to tell the patient before anyone else and ask permission to tell anyone else lest they be

sued. And she said she wasn't aware of that. The practice in Singapore is the opposite of that. I'm not saying that in every situation you should talk to the family first because you may really have to make that judgement call. And so we have to be very sensitive to that. ” (Doctor 03)

### ■ Working with families on disclosure and decision-making

Doctors said that the situation for patients in Singapore is the reverse of the legal model in most cases, particularly in cases involving elderly patients who have adult children who are paying for their medical care. In Singapore, the family expects to be told any bad news first, and then the family members decide, with or without the doctor, how much they want the patient to be told. In some cases, the family members attempt to control and dictate both disclosure of information and type of treatment right from the start, before the diagnosis is even known. Many doctors described that they do collude with this system, and some doctors described being placed in a difficult situation when patients who have been referred to them arrive completely ignorant of their diagnosis or seriousness of their illness, and even ignorant of why major procedures such as surgery have been performed.

” I think that when you practice 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)

” So everything from, say, treatment decisions to say, for example, you know, if clinician says that in my view the goals of care have shifted, it's now going into comfort measures rather than curative, and then family will say something quite different. And we'll say that, "Well but, you know, in terms of taking informed consent, we need to try and understand how your Mommy or Daddy feels about it"; and they say, you know, "Better don't tell her, she's not going to be able to make a decision", "She's not educated", "She's in such pain", whatever. And then they will try and bargain for some of that shift in the spectrum of how much autonomy we want to give to patient versus them, versus you know, us. And there is some sort of communication or bargaining. ” (Doctor 13)

” So I just use very general terms, to see if she understands or not about the condition. Sometimes if they really don't want the patient to know, before the patient steps in, they will bring a note and ask the clinic assistant to bring [that] in first. "My father [or mother] does not know the diagnosis. Please do not disclose." ” (Doctor 63)

## 2.2 Family patterns of disclosure and decision-making in elderly patients

### ■ Families try to protect patients through non-disclosure and collusion

Family members who try to prevent disclosure by doctors to patients, and who

try to make decisions for patients, appear to be doing so out of good intentions. All the doctors who described such actions said that relatives were well-intentioned in their actions. The relatives were generally trying to protect the patients from the burden of knowledge, the burden of responsibility of making decisions, and in particular the prospect of 'losing hope' if given bad news.

“My own personal approach is that I find out why; almost always I receive the same answer: “I don’t want this person to lose hope.” Yeah, then you start to explore a bit more.” (Doctor 63)

“The reasons given to me sometimes were that the patient wouldn’t be able to cope with the news or that he wouldn’t be able to accept that he has cancer or some terminal illness. They suggested that the patient might feel depressed, they may want to commit suicide or do something very stupid. I tell them that that’s not usually the case.” (Doctor 16)

### ■ Many elderly patients relinquish decision making to family members

Interestingly, not only were adult children trying to protect their elderly parents from the burdens of knowledge and decision-making, but doctors described many elderly parents as being willing, or wishing, to defer to their adult children in making decisions, or understanding the full facts of their illnesses. The doctors found that where many adult children were insisting that they should be making decisions for their elderly parents or that their elderly parents should not be told of their diagnosis, these elderly parents were themselves not tending to ask the doctors for information or seemed happy to pass decision-making over to them.

“A lot of time in the West, we usually approach the patient, we work with the

patient toward a certain goal, but here it is different, a lot of times, either the patient defers to the family in terms of decision making or, they may be too ill at a certain point to make decisions when you first meet them. The family becomes a very important aspect of decision making. So a lot of times we work with the family rather than the patient. Either they are too elderly or they decide to leave the decision making to the family. Or they are too ill. Occasionally we do have patient who can make decisions on their own, and we do as far as possible try to talk to them.” (Doctor 63)

“I think if you look at the West, autonomy is very important. “Tell me first, then I decide whether to tell my family.” But over here, being Oriental, being Asian, I think the family unit is very strong, and there is always a deferment or transfer of autonomy many times, from the elderly person—the grandfather, grandmother. And the transfer of autonomy goes to the eldest child or the eldest son. And many times you hear “Let my son decide. It is my son who makes the decision.”” (Doctor 61)

### ■ Reasons elderly relinquish or defer decision making

Doctors tended to think that this pattern of protection was because many elderly parents were uneducated and considered by their adult children to be relatively uninformed about medical issues.

“Interviewer: Even when given the choice, the elderly would defer?

“Yes, that’s right. I think it may have to do with—I’m not very sure—it may have to do with education. A lot of the elderly are not very well educated, whereas those in the West are probably better educated. And, therefore, our elderly patients feel that they may defer to their children who know more, and perhaps it has to do with wanting their children to be involved as well.”

(Doctor 63)



However, it is not evident that it was as simple as an issue of difference in educational levels. There were accounts which suggested this was not merely an issue of lack of education or knowledge, but more the adult children having difficulty trusting in their parents' resilience in the face of adversity, or having a different attitude towards decisions about treatment at the end of life than their parents themselves may take. In some situations, the elderly were able to assert their own preferences, but in others, the elderly parent was gracious and more concerned about maintaining harmony than in achieving their personal preferences.

“[My father] went through a procedure and he became acutely breathless. I'd spoken to [father's doctor] and I said, “He doesn't want to be intubated.” And he said, “Okay, let's try the non-invasive ventilation.” So we tried putting on an oxygen mask. But he was very uncomfortable with it. I said, “Let's just put it.” And he said no. And he told [the doctor], “Don't listen to my son, listen to my wife. She knows what I want.” And then I backed out [of the discussion]. Fortunately he came through that. But the idea is that, he and my mum are very, very clear. They'd talked about this again and again. They said they know exactly where each of them stands.” (Doctor 60)

“My experience tells me that families are very important. And the power of the family is both explicit and implicit. I mean, most people when they talk about the influence of the family in the decision making tend to think of the scenario where the patient doesn't know very much or he's a bit frail and doddery ... and the family takes over. Well that's only part of the equation. I have an equal number of patients who actually, I think, if left to their own devices would probably decide one way but for the sake of their family, decide another way, in order to preserve family harmony. And I have at least

half a dozen patients where this has become openly [the case], “Actually I don't want. But you know lah, my children are, 不舍得 [Cantonese; translation: cannot bear it]. So I will try.” (Doctor 05)

### ■ Family dynamics and individual members' interests

Although most of the decisions of adult children were ascribed to positive motives such as protection, in some cases doctors could ascertain that adult children might be making decisions which weren't the wishes of their parents or even in their best interests, but motivated by the children's own interests or emotional reactions to the end of life.

“And in order to get her more comfortable I actually probably needed to increase her medication and, maybe, she might get a bit drowsy. The other thing was that she hadn't slept in about a week. And I thought, you know, if I gave her some sedation and let her rest, it might be... [pauses] it might give her some symptom relief. But her daughter was dead against it because her daughter wanted her mother to be able to communicate. Or she wanted to be able to communicate with her mother. She was so consumed by her own grief that it wasn't, it just wasn't possible to get through to her. And then I spoke to the patient's husband, this girl's father. I explained to him what we were trying to do. He said to me, “I understand what you are saying. 但是我的女儿不能接受 [Mandarin, translation: But my daughter cannot accept it].” The daughter cannot accept. And because of that, he was also prepared to let his wife be like that.” (Doctor 05)

“You know the ones who don't want to let go, right? And they don't want to let go because of misguided reasons of why they think their father may need [more treatment], but a lot of the time when I personally deal with these families, I think

they feel guilty. Okay, because oh, they feel, “Oh! I didn’t have enough opportunity to spend time with my father when he was well, so it’s my fault that I can’t support him and take care of him.” So one of the most important things that we need to do as physicians, I think, is to remove guilt. And we do that well. So [we say to the family], “It’s his illness that prevents him from being sustained. It’s got nothing to do with you. Okay, you’ve done well. You’re a great son. You’re a great daughter. Okay, you’ve done a great job taking care of your parents.” So all these we...[pauses], at least I, tend to do this repeatedly.” (Doctor 08)

### ■ Not being a burden on the family

A further complication, of course, was the fact that most elderly people were dependent on their family for both care and financial support, and their decisions may be coloured by a consciousness of not wishing to be a burden on their family or a drain on their family’s resources.

“The other concern is sometimes the elderly may be worried that their ... ultimately my family is going to care for me. They may need to make certain decisions because the burden is on them. Financial burdens, physical burdens and so on. I suspect that also plays a part in some of these elderly patients. And they don’t want to make certain decisions, which may burden their families because of this unsaid [concern], you know.” (Doctor 63)

“I mean their dear wish is to go home and spend their days at home. But there is a problem at home because they live with an elderly spouse and the children are very busy with their own lives and things like that. They have their own children to deal with. So it depends then on how the dynamics play out, and how the resources play out because if you have a patriarch who says “ok die, die, I want to go home. I don’t

care what all of you think.” Then sometimes the children crumble and say “ok, we’ll take the old man home” even though they nearly pengan [Malay; translation: collapse] from the stress. But there would also be other people, you know someone else who might say, “Actually I do, I really do want to go home. But I can see that I will be a burden and my family will be very stressed so I accept that I will go to a nursing home or I will go to a hospice.” Ok so these are decisions that are played out every day in every hospital. That’s quite absurd and even though in a discipline like palliative care, we say that we like to respect people’s choices and we know that sometimes in respecting a choice, we may adversely impact on the family. And the patient himself may not want that at the risk of disrupting family harmony, being a burden etc. So you know that’s a common example. And we accept that.” (Doctor 05)

## 2.3 Family patterns in making decisions for younger patients

### ■ Independent decision makers

From the accounts of the doctors, there may be some phases in life in Singapore when people are more independent in making treatment decisions, and some phases when they are less so. One doctor gave an account of patients aged around 40 to 55 or 60 years who are independent in decision-making, and younger adult patients who retreated to a child-like position when ill.

“Let’s start with the middle-aged. I’m personally getting near the age group. But let’s put it at forty to fifty-five or up to sixty, those two decades of people. I think the majority of them wish to make decisions for themselves especially concerning [the] end of life. But I’ve observed that, for those between 55 and 60, they tend to have a big

family. Even for the unmarried patients, their experiences are pretty similar to those older. Below that age range, people are easy to approach for talking to about their diagnosis and treatment. And they're generally the decision-maker if not the primary decision-maker. I've observed that among the thirty to thirty-five age group, and I think it pertains to this particular culture, their parents are still influential on their decision-making. Perhaps it's related to the fact that they had lapsed from a healthy to an ill state, so their coping mechanisms have changed. From a previously independent mentality, they revert to a more childlike state and pass decision-making back to their parents, like children and teenagers do.” (Doctor 16)

Doctors who mainly treated adult patients who are young and economically active found that these patients were very independent in making their own decisions.

“Normally early [names type of] cancer is about 30 plus.”

Interviewer: 30 plus? That young?

“My youngest patient in [names work context] is 26. She came in as a stage 4 [cancer]. Yeah. She died in about 18 months. And the only reason she saw me was because I was the only one who wanted to help her conserve her [appearance] and give her adjuvant [auxiliary] therapy because everyone else just wanted to remove everything and she has very sensitive because she was single; and she said she wanted to be put in the coffin, with her [appearance] intact, whether or not she died from cancer because she said she knew she was going to die. So she was not going to die from [major disfiguring operation].” (Doctor 07)

### ■ Passivity of mature minors in end of life decisions

We did not interview many doctors who treated patients under 21 years, the general age of legal majority in Singapore. The

doctors we spoke to who did treat legal minors found that parents in Singapore are very protective of their children, even those who are older adolescents or nearly adult. In the well-educated society that Singapore is, these children would be highly educated; but nevertheless parents tended to dominate decision-making and to give legal consent, with children staying relatively passive and uninvolved, or being heavily influenced by the views of their parents.

“I remember I had a [names disease] patient aged eighteen to nineteen about two years ago. His condition progressively deteriorated till his passing away. I recall that his father was the decision-maker throughout that period. The patient never asked about his condition. People who did ask were his family members, in particular, his father.” (Doctor 16)

“And it's also a bit of the family unit. I mean in the family unit so much of what the children think is influenced by the parents. And again the parents are not always of the same mind. So. That's part of the issue I think. [...] I think because in the local context the parents have a lot more influence on their children, 'assent'<sup>1</sup> to the doctor will always be there, how much of it is parentally influenced, sometimes it is hard to decide.” (Doctor 43)

“And I think in our Singapore situation it is a lot more exacerbated by the fact that the family still consider them [adolescents and those under 21 years] as children. So a lot of them are not allowed to participate in decision-making.” (Doctor 41)

### ■ Children protecting their parents, reacting from suppressed feelings

Once again, the motivations of the parents were usually the protection of their children, who were also [like for the

elderly] feared to be at risk of 'losing hope' if they were to know the seriousness of their illness or poor prospects.

“We find that a lot of our [paediatric] patients protect their parents. So that they don't make their parents upset.”

Interviewer: Tell me what happens in these family systems. We need to unpack a bit more.

“A lot of these parents will—basically they don't want the child to lose the will to live, they don't want us to tell the patient it's so serious. Basically they want them to fight, and they want to give them hope. But a lot of these kids will experience death when they are in the ward. Because some of the other children don't make it. It may not be expected because they had some bad infection. So they have some experience with death. But because they are not really allowed to talk about it, they don't. And they would act up in different ways—being non-compliant with medication, not wanting to come to hospital. They are just difficult. Sometimes at home their parents can't control them. Because if the child is fifteen or sixteen years, the child cannot be forced. And yet they don't want us to talk to them.” (Doctor 41)

### ■ Doctors prevented from talking to minors about their diagnosis and care plans

In some situations, doctors suspected that older children and adolescents were often just echoing their parents' wishes and weren't necessarily happy about the decisions their parents were making. However, in these cases the doctors were often prevented from being able to speak to these children alone and could not verify what the children's real wishes were.

“These are teenagers, eighteen [years old]. This was kind of silly because our ward was in [name] Cancer Centre. So you tell them when they walk into the ward, they're

going to see and they're going to read. And they [the parents] say [to the teenager], “Oh, because they don't have beds elsewhere.” The whole thing becomes ridiculous. But we try to work with the family and don't want to alienate them. So we don't want to go against their wishes. What most of us would say is, “We want you to tell the child,” and we tell them why and all that. It usually would take a few minutes for them to agree. But we tell them, were the child to ask us, we will not lie. So it depends on what the child asks. If they ask the nurse or one of us, we would tell the truth. But in the ward, one parent is allowed to stay with the child. If the child isn't left alone, then they never ask ...” (Doctor 41)

“Of course if the child's older, we'd tell them we would want to listen to what the child's opinion is. We had recently a case where I felt the child was just saying yes for the parents. And we have never managed to get the child alone. But we guessed from certain things they say to the nurses at night, when the parents are asleep and all that, that he really isn't happy about continuing treatment.”

Interviewer: Okay. How old is this child?

“He's, I think, fourteen or fifteen.”

Interviewer: So he would know.

“He does, he does. He had a bad time with the treatment you see. And he didn't want to go through with it again. But the family didn't want to let go. And a lot of the time they feel they don't have the choice, that they should carry on. Because the choice would be to give up and let him die.” (Doctor 41)

### ■ Doctors and parents who have difficulties stopping curative treatments for minors

As with the treatment of the elderly, however, doctors were more able to see that in some cases the parents of children and even their doctors were making decisions based on their own emotional journeys,

and in particular whether they were able to let go of their children who were facing death.

“In general we have more problems with our oncology patients. For them, when we first started we’d go all out to treat, to treat, to treat. And it’s only when we find that we’re just causing more problems than curing that we tell them that we should maybe think about shifting our goals of care. So it’s very hard for them to let go. Because they have been trained to be very careful about exposing the child to infection, about making sure the child eats clean food. And monitoring blood tests. And if they are to suddenly switch off—in the sense that they stop monitoring, and give the child whatever she wants and all that—it’s very hard for them to make the decision. It often takes a few months before they themselves have to be convinced by their seeing how much it’s not benefitting the child.” (Doctor 41)

“I get frustrated, because [pauses]... it’s because of my own personal biases. I would probably consider ‘giving up’ earlier compared to the oncologist who’s thinking, “Hey, one more round”. It’s that kind of thing. And, in paediatrics particularly, there’s a big problem because it’s the parents who are asking for the further chemotherapy, and the further aggressive therapy. And I never really know how much of that is the child’s decision. It could be the child’s decision, [but] I don’t know, as it is a family thing. That is something I struggle with. So sometimes I feel that we are all just moving down this aggressive route, and there’s not enough voices gone into, “Let’s go a bit more into comfort care and let the kid have a chance to play and enjoy whatever couple of months he has.” (Doctor 43)

“So I said, “Why is he getting this?” So she [the treating doctor] said, “He very poor—thing ah, he’s only sixteen years old”.”

Interviewer: So you do not let a sixteen-year-old die.

“It’s difficult for her. I think so. In [names specialty], we get very close to the patient. We get very close to patients and the whole family. This is [due to] repeated visits, you see? So the rapport is much stronger than, say, with other doctor-patient relationships. Yeah. So it is difficult.”

Interviewer: So, sorry this is my psychiatry hat going on. I start wondering, if the doctor can’t let go, how does one expect the mother to let go?

“Yes! That was my exact question. So one of the [my] projects is to help the doctor recognize [the problem], and help the doctor, because if the doctor cannot let go, then that is the time when the doctor needs help.” (Doctor 14)

## 2.4 The practical consequences of not involving families in decisions

The doctors said that it was neither realistic nor possible to speak to patients first about their condition, or to exclude families from making decisions or medical disclosures to patients. Instead, the common practice in Singapore was to speak to the family members first before breaking bad news to patients. If a doctor tried to speak confidentially to a patient first, this would upset family members who might lodge complaints against the doctor, threaten lawsuits or take the patient to another healthcare provider.

“Oh! Huge issues here, partly because 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. These reasons ranging from yes, it is to the patient’s best interest that we involve the family in decision-making to the more



cynical, “protect backside, patient dies, it is the relatives that are going to sue you, not the patient”. ” (Doctor 13)

### ■ **Compromise solutions put to families regarding disclosure**

Most doctors did believe that patients had to know about their diagnosis in general terms, to understand and agree in general terms to their treatment, and to know in broad terms if they were at the end of life. This was important to doctors because patients did have to understand why they were undergoing uncomfortable or even painful procedures, and because patients should have the opportunity at the end of their lives to settle their affairs and say goodbye to people important to them as they wished.

“ She had breast cancer, and she seemed to prefer her family to take charge of everything. It went on until the point when the family said I was to send her for mastectomy without telling her about it or the diagnosis. But I said, “You can’t do that! She’s having her breast walloped.” ” (Doctor 03)

“ For someone who doesn’t know the diagnosis, I’d speak to them separately, I’d try to get the family to understand the importance of her knowing the diagnosis, so as to be able to get the treatment. So as I said, using the same strategy to convince them that it’s necessary but telling them that it doesn’t mean you have to use terrifying words, to give every bit of information. But she has to understand that it’s serious, serious enough to have serious treatment, enough to give consent. So usually that works. And then I have to go back to the patient to find out if she wants to make the treatment decision herself, or she wants to delegate. ” (Doctor 03)

### ■ **Unproductiveness of hiding the truth**

In fact, many doctors said that most families’ attempts to hide information from their parents were doomed to fail, and elderly patients and children tended to know what was happening, if not from their setting then from the behaviour of those around them. The problem then with withholding information was that it blocked any ability for the patient and family to communicate honestly about the situation, while not enabling any truly blissful ignorance.

“ And she [a patient] lived with a very protective daughter who obviously found it very hard to accept [the situation], and unfortunately, she had a very aggressive cancer with a prognosis of three months or less. And from the day she was diagnosed, her daughter told the attending physicians not to tell her the diagnosis. When she [the patient] came to me, she was illiterate and she didn’t know it was the Cancer Centre. She actually said, “Why am I still having so much pain and problems, when the surgeon has taken out this growth, this lump, and I should be ok by now?” That’s why, in terms of damage control, palliative care is [not best offered] at the tail end. If you had handled it better upstream, in a more sensitive and easier way...[tails off] I don’t know what to say. What do you say to her? “The truth is that you have symptoms because of the cancer. The cancer is still there!” You know? “No, no! The surgeon said it was technically too difficult to operate, which is why I must take oral medicine.” And I said, “What is it that is so difficult to operate that it doesn’t get better?” And her daughter said I mustn’t tell. So that’s why I had to skirt round that issue. That was the first time I met her, and I hadn’t had time to get to know her. Skirt round the issue, and skirt round the issue. ” (Doctor 03)

### ■ How to break bad news to a patient

The doctors we spoke to all disapproved of full collusion of doctors with families in completely hiding diagnoses and terminal prognoses from patients. Instead, most of them advocated a sensitive approach where they first approached the family and prepared them for the news, then discussed the patient with them and helped the family to decide how information-giving should be broached with the patient.

“And so, they [the patient] will know. Eventually, they will know. It’s how you tell them. So, like I said, discuss with the family. If the patient is very much in charge of himself, discuss this with the patient and the family together. Usually, they [the doctors] try to do a bit of investigative work. They would sugar-coat it, in the local context we sugar-coat it and tell a little bit to the family first, and then decide, “You tell, or I tell? Somebody has to tell.” Sometimes, the family cannot cope. [They] say, “Doctor, can you tell?” I say, “Sure, I’d be happy to.” But even before I tell, I’d say, “Let me see him for a few times. Let me gauge this person. You tell me what he’s like at home. Then, let me talk to him. Let me gauge his responses. Then, we’ll find the right words to tell.”

Interviewer: So, sounds like for you, not telling, which was discussed at the [medical ethics] conference, is not an option. But, at the same time, you often involve the family before you tell the patient.

“Unless the patient asks me, “What did the [investigative test] show? Is it good, or is it no good?” And before that, even when they get consent for the [test], we’d say that, “Well, there is a suspicion that your [names tissue] is not growing healthy cells.” They get the hint. We don’t use the word [names a type of cancer] or ‘cancer’ straightaway. It’s very devastating. Even if it’s 24 hours or 48 hours, you give the patient a little bit of time to sink in first. And hopefully, they don’t [names a crisis event] that night! But

it’s tough, you know? Because we also have to [tails off]... You tell them straightaway, “Uncle, you’ve got [a type of cancer]. You’re going to get chemotherapy. You’re going to die.” You can’t say things like that. It is not fair for... I feel that it is not fair for that patient. Unless the patient has said, “I come prepared. My GP has told me something.” Or: “My doctor said I may have [type of cancer], what do you think?” And then you know the patient is already prepared, so you can be up front.” (Doctor 14)

## 2.5 The role of finance in family decisions

According to the doctors, finance plays an important role in how families in Singapore make decisions. In the current medical system, the majority of both the elderly and legal minors are financially dependent on others to pay for their medical treatment. In Singapore, the person who pays the bills tends to have a very large say in the medical decision.

“At the end of the day it’s who pays the bills, right?” (Doctor 19)

### ■ Problems with paying

There were practicalities of the person paying the bills having to make judgement calls about how much they were willing to pay for and what other claims they may anticipate on their financial resources in the future. In addition, patients and other family members recognised and deferred to power that was endowed on family members who paid for their bills, who might not be the same person as the main caregiver. Doctors alluded to underlying reasons for this practice.

“He [the doctor] said, “In the UK we don’t discuss with the family. It’s partly because everything is paid for by the NHS.” Whereas here the family are the ones who are paying

for the healthcare. Singaporeans are very pragmatic. It's who pays, very often. We've had this situation with elderly men. A lot of [names particular illness] patients are elderly men. And then you say, they could get better. But some of the treatments are very expensive and they are not covered. I heard somebody come up to me and say, "We have to talk to the family. Because they have to pay for it." ” (Doctor 60)

“ I think sometimes there's confusion, especially for my social workers in terms of decision-making for discharge planning. The main spokesperson for example can be the daughter-in-law taking care of the patient with the stroke. But she's not the financier. She doesn't pay the bills. It could be the second or third son who's paying the bills. For caregiving issues, you know, the training and all the psycho-social support, we might deal with the daughter-in-law we might plan that they need to be discharged. The next thing we find out the son comes in and says, "No, you can't. I have to pay for the maid. We can't afford the maid," or "The maid's no longer here." You can't even discharge the patient. So—very conflicting?

The family member giving the care may not be the one with the power to make certain decisions, pay the bills, procure the maid, get meals, get home care, nursing care. ” (Doctor 19)

### ■ Filial duty and end of life decisions

Adult children were, at the same time, very conscious of their duty towards their parents. This sense of duty and obligation was described by doctors as 'filial piety', an Asian notion that was most obviously acknowledged by Chinese, but also by Malays and other races. Interestingly, the concept of filial piety or devotion to parents has been recognized by the government in law through the Maintenance of Parents Act. This underlines the societal expectation that adult children would look after their parents—which was both an issue of obligation and also, for some, of maintaining 'face' in Singapore society.

“ In terms of culture again, there is a certain dynamic in our family relationships that suggests that a child, or the children of a patient, has failed in his duty in some way,

### Medical Cost Pressures for Two-tier Families

Henry is a 32-year-old man who is married with no children. He has two elderly parents and an autistic brother to support on his monthly income of \$2500. Henry's father has end-stage renal disease, and his mother suffers from hypertension controlled by medications. His wife's monthly income from part-time work is \$800, which contributes to the care of her elderly diabetic mother and her father, who is mildly hypertensive. She has no siblings.

Under current means test criteria, only Henry's wife's dependants qualify for medical subsidies under means testing since her income divided by 3 yields a per capita income of less than \$300. Her husband's per capita income calculation cannot include his autistic brother even though his parents are elderly and unemployed and he has to support his brother. Under means testing rules, his calculated per capita income only provides marginal or nil subsidies.



if he didn't press for everything possible to be done right up to the end. And that whole idea as it were, bringing your parents home to die in peace, is just not acceptable in this case. You might lose face, because you might be accused of not demanding more treatment to preserve the parent's life. ”

(Doctor 11)

### ■ A medical perspective on filial piety

In some cases, the issue of filial piety, duty and devotion to parents and the need to maintain 'face' might lead to children insisting on treatment for elderly parents even when treatment was futile or caused suffering for little gain, and additionally cost a great deal of money. In such situations, doctors said that it was helpful for the children to be told by the health professionals that they did not need to insist on treatment in order to be seen to be filial.

“ Yes so that's why end of life is such an important issue because it tears apart your whole.. you base your entire Confucian Asian philosophy of a country, or your identity as a

country that the family is the most important thing, because that's your whole concept, the Singaporean Asian concept of filial piety. You can be very pious, you can have great filial piety if you're not paying for the bill. But it's really hard to have filial piety, or to want the best for your parents which is what you want...when your Medisave<sup>2</sup> is finished, you know, hospital bills are coming up to a huge amount, it's really, really difficult.. and our.. a lot of our healthcare system is means tested if your income is so much but your savings are so little, then that's it. It's called intergenerational transfer of resources. ”

(Doctor 06)

“ [A]ctually a lot of them were really relieved that somebody brought it up. Because of that whole filial piety [concept]. “I don't want to say I'm not going to provide the care. But when someone professional says, look I think it may not be in the best interests of your mother to put her in the ICU [intensive care unit] with the tubes and everything.” So it's actually good for me to bring it up because you want her to be comfortable and happy. AH! [mimics

Husband				Wife			
Income	\$2,500			Income	\$800		
Expenditure	\$4,491	*		Expenditure	\$1,202	#	
Dependants	Condition	Est. Mthly Cost	Note	Dependants	Condition	Est. Mthly Cost	Note
Father	Kidney Failure	\$1,808	1	Father	Hypertension	\$30-\$100	4
Mother	Hypertension	\$30-\$100	2	Mother	Diabetes	\$30-\$100	4
Brother	Autism	\$30-\$100	3				
Mthly Surplus/(Deficit) :		(\$1,991)		Mthly Surplus/(Deficit) :		(\$402)	

\* data from Department of Statistics Household Expenditure Survey 2007 for 3-room HDB flat, plus extra medical costs

# data from Department of Statistics Household Expenditure Survey 2007 for 1/2-room HDB flat, plus extra medical costs

1. Dialysis costs from National Kidney Foundation website, \$130/dialysis+ GST, 3 times weekly but excluding transport
2. Costs of medication at subsidised polyclinic rates conservatively estimated
3. Institute of Mental Health outpatient care + medication conservatively estimated
4. Costs of medication at subsidised polyclinic rates conservatively estimated

**sounding relieved] Oh they were so happy that someone brought it up. But when you position it that way it wasn't that they were not being filial by not paying another 20 thousand dollars more to the hospital. ”**

(Doctor 06)

As previously discussed, doctors said that elderly patients were, in turn, often conscious of their illness being a drain on their adult children's financial resources, which was also meant for these children's and the grandchildren's medical needs in the future. Some very reluctant to be financial burdens on their families, and might decide not to accept treatment so as to save their children's money and prevent an intergenerational transfer of resources which would leave no reserves for the medical needs of the next generation.

## 2.6 The issue of whose interests are foremost

### ■ What happens to 'best interests' in the family context?

In Western medical practice, the general principle followed is that the patient makes decisions for himself or herself where possible, and if this is not possible the doctors have the duty to make decisions on behalf of the patient in his or her best interests. The doctors we talked to all agreed that this was their guiding principle when called upon to make decisions about patients.

In the Singapore context, however, when families make decisions on behalf of patients and also provide financial support for treatment, it becomes less clear whether these decisions are made in the patient's individual best interests, or whether, indeed, it is meaningful to think of the patient's individual best interests. Are relatives' decisions for patients always in the best interests of patients themselves? In many cases, doctors did feel that relatives

were trying hard to protect the patient and to care for him, even if the decisions might be misguided. In other cases, however, doctors sometimes felt that relatives were making decisions based on their own emotional issues, or on decisions made for the overall benefit of the whole family, as opposed to the best interests of the patient himself.

**“ It's like: think about someone else. Because she [the daughter] was going on about, “My mother can't talk to me. I want my mother to talk to me. If she doesn't talk to me it means she doesn't love me. I want her to look at me.” [...] “Actually the patient knew it [that her daughter's attitude was a problem], and according to the primary oncologist—and we both saw this lady because we both came up to try and talk to the family—this patient admitted to the oncologist that she's the lynchpin of the family: “我是这个家里的老妈” [Mandarin; translation: I am the matriarch of this family]; and [she] had said that, if anything happened to her, those two—meaning the husband and the daughter—“他们两个就是完蛋了!” [Mandarin, translation: The two of them are finished!]. Which is ironic, because this woman was clearly a very capable woman; and I don't know how she managed to not prepare her family. But I think she did try. From what I understood, every time she tried to broach the topic with her daughter, the daughter would cry or the daughter would avoid discussion altogether. So then, again that's difficult. You can't force the issue if people don't want to deal. And that might be just your bad luck. So when all is said and done, sometimes, whether you can die at the place where you want to die is as much a matter of luck as it is of anything else. ”** (Doctor 05)

**“ Some of them turned around and said, “He was bad to my mother. He had so many mistresses, and when he got [names illness], we thought it was just [deserts]. And**

now you want to give him this expensive treatment, and bankrupt us? So we can't pay for our mother's treatment?" So there is no way. I actually had a family [member] come to me to say, "This is going to deplete our Medisave, and if our mother gets sick, who's going to pay for her?" She's the innocent party in this, he's the guy who was a rotter all the way through. So they sort of flatly

refused. What we did was to try and get around it with Medifund<sup>3</sup>. But we can't get Medifund because the children had money. You are eligible for Medifund only when the children have depleted their Medisave. They insist that your children have depleted their Medisave. So the result was that we had to apply to charities. ” (Doctor 60)

---

### Summary

In Singapore, doctors find that they have to involve families in decision-making for most patients, particularly those who are elderly and legal minors, or otherwise dependent on their family for care. Families may expect to be consulted before any information is given to the patient, and often feel protective towards the patient, seeking to hide information or make decisions on the patient's behalf. Doctors say that they have to work with families towards disclosing bad news and involving patients in decisions, and also that there are other factors that affect family decisions apart from consideration of what is best for the patient, such as the welfare of the family, finance and filial piety.

---







# 3 HEALTHCARE FOR THE DYING IN SINGAPORE

“I mean if Singapore does not look into all these, our medical system will also break apart. That’s my point. If I’m in the private sector I’d be happy because I can see all these patients. But there will come a time [pauses]... At the end of the day it’s the patients that will suffer, because if patients cannot pay, they’ll say, “How to? Die lah.” It may come to that point. So for the good of the public, there are certain loopholes which need to be looked into.” (Doctor 76)

The doctors interviewed had much to say about the practical problems inherent in the Singapore healthcare system, which can have an impact on end-of-life care.

## 3.1 Difficulties with the current healthcare institutional structure

### ■ Medical homelessness: self-paying, self-referring and consumer driven healthcare system

The current healthcare system in Singapore comprises many different types of healthcare, many of which operate independently of other types of healthcare. There is a large private general practice<sup>1</sup> and specialist healthcare<sup>2</sup> sector which functions independently of the government-subsidised polyclinic<sup>3</sup> and ‘restructured’ hospital<sup>4</sup> system. People can choose whether to seek treatment in the private specialist or ‘restructured’ hospital system, and can refer themselves to

specialists without needing a referral from polyclinic doctors and GPs. Patients are therefore seen for different ailments and at different times of life by different doctors in different healthcare settings, with no individual health professional having a single overview of each patient’s overall health and wellbeing.

### ■ Co-payment & financial drivers, intergenerational transmission of care burdens

“So in Singapore, you’re born, you see O&G, obstetrician who really doesn’t see you... So he pulls you out. The obstetrician pulls you out but he’s not responsible for the subsequent health, right? Then [he] hands you over to the paediatrician, or the GP, who takes care of you. If it’s a paediatrician, he’s legally not supposed to see you beyond a certain age; so even though he’s known you really well as a child, he doesn’t know you anymore as an adult ... and in your adulthood you also will have one system where you see a doctor for your work, you see a doctor for your workplace health. Then, if you then you see another doctor for your disease because your workplace health is only funded for coughs and colds—because that’s your contract with the government or your contract with your employer—then after that, if you have any chronic disease you see another doctor. Then if you don’t like him, you keep hopping around. ... Then you reach an age where you deteriorate.” (Doctor 06)

Another consequence of the Singapore system is that there is often no healthcare professional that a patient has a long-term, trusting relationship with; unless, paradoxically, that patient has a chronic illness which requires specialist long-term care from doctors such as paediatricians, geriatricians and rheumatologists, whom patients then develop more trusting relationships with.

### Important drivers of the Singapore healthcare system



“(I)n the old days we used to call [names specialty] the practice of general medicine in the young. Because [names two disorders], a lot of these [specialty] diseases which are more severe, tend to affect the middle aged or the younger person. Because of the advance in care, most of my patients now grow old with me.” (Doctor 59)

#### ■ Difficulties with moving from hospital care to home care

One consequence of the independence of different parts of the healthcare system is that there can be problems with the transition of patient care when they need to move from one type of care to another. For example, although there is good professional support for severely ill patients in hospital, there is a severe lack of resources for the medical care of patients who wish to go home to die amongst their loved ones, and families are often left to fend for themselves in terms of the burden of providing care for dying relatives or purchasing what they need from the private sector<sup>5</sup>.

“I suppose the failing in hospitals is that they still don’t have a sufficiently

robust interdisciplinary mechanism for us to come together to discuss our patients and, in one sitting, run through all these medical issues. Currently in this hospital, while we have good communication links open, we’re not effectively working as one single team helping to manage [patient care]. So we could improve on the level of coordinated... [does not finish thought] but clearly, depending on the magnitude of the problems, certain people are more important in taking the lead, solving some of these problems; and sometimes, it is more the social worker and nurse clinician who make the decisions. From the infrastructure perspective, when it comes to bringing everyone back, the long-term answer is to bring the patients home. But when we look at what’s available to support them, I think it’s often a lack of awareness and education about what’s available.” (Doctor 18)

Another problem is that if patients die at home, there may be no medical practitioner who knows them well enough to sign their death certificate.

“(T)here are some challenges in certifying the death of patients in the home setting, but they’re not insurmountable. Then there are the support arrangements: they need a hospital bed, and mini oxygen cylinders. None of these are subsidised. It’s a private arrangement between the family and private companies. Physiotherapists making home visits. [...] So the financial structure, both physical and manpower are not conducive to [dying at home].” (Doctor 18)

“The problem is that people would like to die at home. If you talk about Malays especially, they do not like autopsy. They just don’t like their bodies to be dismembered and cut away, and then be told it’s the same diagnosis [as they were told all along]. They want to be buried in a whole piece. So of course they’d rather that the patient passes away at home, where the doctor certifies



death. And also the Malays don't keep the body for more than two days. So they want to get it done as soon as possible. So because of that, even for non-Muslim families, I'm sure they would want the patient to pass away at home. The loophole in Singapore is that cancer patients are well looked after, but not for chronic illnesses like end-stage renal failure, and for those old people with high blood pressure and diabetes and are bed-bound. Sometimes even if they're not so bed-bound, their family goes to the polyclinics and collects medications for them. The problem is, polyclinics don't have this service. They're only eight-to-five. For somebody who's been following up with the polyclinic and passes away, who do you call? Because there's no family doctor. Or do you call the polyclinic? No, right? They would say no, eight-to-five only. If you pass away at six o'clock, polyclinic doctors don't do house calls, basically."

Interviewer: They can't.

"Yeah, they can't. And there's a big group of these people who follow up with polyclinics, who do pass away. And then, the question is who's going to certify death

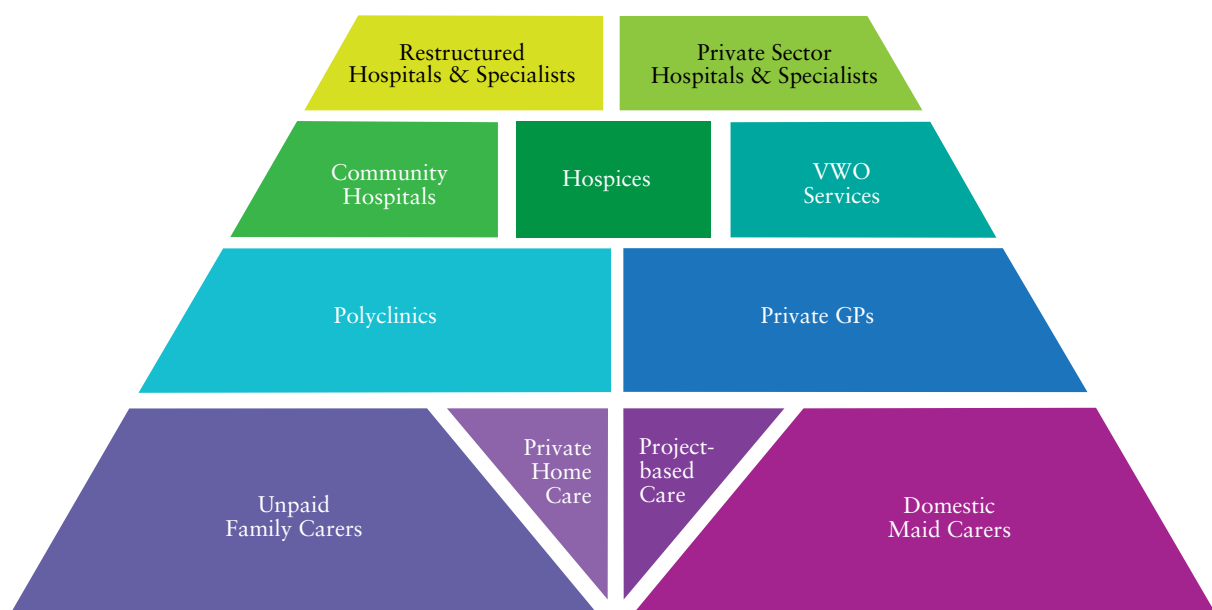
when they pass away? So I think this is a big loophole, a big gap in public healthcare, if you ask me. ” (Doctor 76)

### 3.2 Finance and the healthcare system in Singapore

#### ■ Difficulties for families in affording care for chronic illness

The current financial arrangements for healthcare in Singapore are largely based on the assumption that inpatient hospital care is likely to cost the most and therefore require the most subsidy and assistance. This is certainly true in the more traditional model of illness: for example, where a previously well patient may suddenly suffer a heart attack and need hospitalisation; and then the patient may either die, or recover and be discharged to outpatient care. There is a sudden and large expenditure at the acute hospital, with not much cost to care before or after the admission.

Nowadays, however, illnesses are more chronic in nature, and in many end-of-life scenarios the patient will have a long,



A conceptualisation of the participants' descriptions of the Singapore healthcare system for people at the end of life.



slow decline punctuated by crises, with an increasing need for care before he or she dies. This means that patients may need to be discharged from acute hospitals to community hospitals for rehabilitation; or may need considerable or prolonged care at home in terms of doctors' and nurses' visits, home oxygen or other medical provisions and physical care. The financial system as it stands, however, often makes community and home care, which are considerably cheaper than acute hospital care, paradoxically more expensive for the patients and their families because of the relative lack of subsidy or support. Sadly, many patients who are discharged from tertiary care have already exhausted the financial resources of their families, and even highly subsidised community-based care may become prohibitively expensive. This, combined with the added burden of providing care, constitutes a powerful reason for patients and their families to resist discharge from hospital to more community-based care.

“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.” (Doctor 18)

“By the time they come to us, the financials have hit them, because the first bill has just come to them. And now they're worried, 'Oh dear, if I can't pay, the second bill will hit us.' Number two, they are having to deal with the emotional-psychological aspects of, 'How do I carry on with life after a stroke, after an amputation, after a fracture?' It hits them by the time they come here. So the care counselling has then to work [these things] through with

them. Family dynamics all start coming out, because they'll start arguing who's going to be the caregiver—the primary or secondary caregiver. It's more social once they come here.” (Doctor 19)

### ■ Polyclinics: bridging the gap between private primary care and hospitals

Primary care in Singapore is divided into private and public care, the private care largely being provided by Family Physicians (who are also called General Practitioners or GPs) in the community and in company or workplace-based healthcare, and public care by the polyclinics. It emerged from the doctors' accounts that there has been a traditional rivalry for custom between private GPs and the polyclinics. This has given rise to several bones of contention and anomalies in practice—for example, patients cannot get access to subsidised specialist medical care in the restructured hospitals if referred by a private GP to a specialist, needing a referral from a polyclinic doctor instead. This leads to GPs having to instruct their patients to go to polyclinics to get referrals into specialist care, particularly if prolonged or expensive admissions or care are anticipated, which leads to further crowding of the overburdened polyclinics. If patients go into their specialist treatment at too high a class and subsequently need to be downgraded in their treatment class, they have to undergo assessments by medical social workers which involve disclosure of all the incomes of the entire family, which many families find humiliating or unacceptable.

“Interviewer: Explain to me how going via the polyclinic helps?

Doctor 35: “They get subsidised care. They go in as B2 or C class patients but they don't get to choose their specialist. It means they are assigned specialists. But I think that if you have a tumour anyway, then, ai yah,

don't care! Go in via the polyclinics to get subsidised care and the subsidy is quite a lot." [...]

Interviewer: Revise for me. If you referred me as a GP to a hospital, how does it work? Which class would I go to?

Doctor 37: "You are A class straight away. That's been the government policy. It's been ten to twenty years down the line. We have been quarrelling with the system about this dumb thing."

Interviewer: I didn't realise that.

Doctor 37: "Once it's a GP referral, it's to A class straight away."

Doctor 34: "Or paying class."

Doctor 35: "Or B1 and above."

Doctor 34: "No, that's if you are hospitalized, but if you are outpatient.."

Doctor 37: "If you wish to downgrade, you have to go through the medical social worker which the patients are unwilling to do. The social worker checks your income and pay slip, to justify to them why you want to be downgraded. To avoid the hassle of having to downgrade through the medical social worker, why don't you go to C class [via the polyclinic] as a non-paying class, subsidised patient."

Doctor 34: "And if you find that they have assigned you a lousy specialist who can't operate on you, then you can choose to upgrade. You do have the option."

Doctor 32: "That's if they refer through the clinic. If they refer through the ED [Emergency Department], then the ED admits according to the.."

Doctor 35: "There are only two ways you can get into hospital in a subsidised way—one, via the government polyclinic, two, via the Emergency Department." ”

“It used to be cough and cold, and over the years, it's become more of a chronic disease management centre [at] the polyclinics. This is the fact, because of the subsidies. In Singapore, [for] cough and cold, people do not want to come and wait for a long time in polyclinics. People can

just go to see their GPs and it is perfectly fine. And for chronic conditions, they took medicines for condition like diabetes. They can still afford to go to the GPs, but once they get complications, their co-morbidity would have doubled, that means they [need to] get 5-10 medicines. It completely makes sense economically for them to come and see us. [...]

Interviewer: How many patients on average do you all see [at the polyclinic]?

"Okay. We have different rules now. For example, I only see the STC—the second tier clinic. I see about, say, 40 a day, which is 8 to 1 and then 2 to 6. About 8-9 hours, 40 patients. But the doctors who see the walk-ins, the simple chronics, can see up to 70 a day. [...]

"We (the polyclinics) are trying to collaborate with the GPs for years, but I think the GPs are very wary of us because it's still their patients, it's perceived as their patients. But once there are complications, all the patients will swarm to us. They lose their patient. So they view us as competitors.

” (Doctor 67)

### ■ 'Slow medicine' needed

The current healthcare system in Singapore is very highly developed in terms of tertiary, hospital-based specialist care, but relatively underdeveloped in terms of more general, rehabilitative or supportive community-based care. This imbalance is being actively redressed, with several community hospitals offering admissions for rehabilitation, and also increasing resources to provide medical and nursing care in the patients' homes. Many voluntary welfare organisations have also been involved in the government's strategy to expand community-based resources, for instance by running community hospitals, hospices, day care centres and ambulatory care services.

“The minister calls us 'slow medicine'. So he did de-glamorise medicine for us. You

can quote me on that. Yeah, we are called 'slow medicine', so the therapy we do is slow-stream rehab[ilitation]. So nobody really has an idea of what exactly 'slow medicine' is but ... it is transitional ... Long-term care would be more nursing homes and the hospices. So we are right in the middle. So we have acute hospital, we have home, nursing home, home care and we are in the middle. ” (Doctor 19)

### 3.3 The healthcare burden on families

#### ■ Financial burden

In Singapore, because of the co-payment system, there is a considerable financial burden of the care of patients at the end of life on their families, particularly if the course of the illness is slow and protracted. This financial burden and payment for treatment means that a patient at the end of life, who is often not (or no longer) economically active and may have exhausted his or her own funds for treatment, has to rely on others to contribute from their own Medisave funds for treatment. These other people therefore have a great deal of power in the decisions that have to be made about medical treatment.

The doctors said that Singaporeans are highly pragmatic and that there is a general acceptance that the person who pays the bills, usually an adult child or parents of a legal minor but possibly other relatives such as siblings, would be the final decision-maker about whether a treatment is given rather than or as much as the patient himself or herself. This was accepted by all—by the doctors, the relatives and the patients themselves—as a fact of life in Singapore.

“The only problem is that, quite a number of times patients would have exhausted their Medisave by the time they come here.

That's why at the community hospital you will see that the social work department is rather strong, because that's where we will have to handle a lot of financial and psychological aspects. In the acute hospitals they're just concerned about sorting out the [medical] problems. ” (Doctor 19)

#### ■ Care burden

The doctors pointed out that it was often the case that the person who had to pay the bills had to work so hard that he or she was unlikely to be able to physically care for the patient. This being the case, the person paying the bills had to rely on other family members or domestic helpers to provide care—this led to practical issues including difficulties for doctors in educating and supporting the person actually providing the care at home.

“The family member giving the care may not be the one with the power to make certain decisions, pay the bills, procure the maid, get meals, get home care, nursing care. What's worse is that a lot of them have now got maids. And some of them would say, "Don't teach me! Teach the maid. I don't need to know." So I've seen quite a bit of that. I think it's terrible. Maids get pregnant, maids run away. And when that happens the caregiver is absolutely distressed and helpless. I think sometimes it's... for example, changing of tubes, care for the stoma [pauses for four seconds] ... a lot of things that are not comfortable to do. So they'd rather get someone and just train them to do. And they [the payors] think if they have to work in order to support the continued care of my father, brother or whoever, if they have to take that responsibility of caring, then how can they work? You know what I mean? They have to bring home the money, right? To support the work, to support the hospitalisation fees and all that. So, they don't have time! So we've tried to have caregiver support groups, for example. So our social department has tried

to have that once a week. We tried with the family members. We offered it to the maids, OK? The employers refused, because they were afraid that the maids might exchange

numbers, and start talking to each other! Yes! It's amazing. He said, "No, my maids do not come for the support group." ”  
(Doctor 19)

---

### Summary

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 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 is a need to debate the healthcare system openly in order to develop new ideas and policies about fairness of access to good healthcare and wholistic, seamless and appropriate care for patients and families whose needs will vary and fluctuate at the end of life.

---





# 4

## LAW AND THE END OF LIFE

“So most of the euthanasia [and] assisted suicide advocates, I feel, are very much in this category of people. They are very, very convinced that they’re right. And I think it’s driven by this need to be in control. So I don’t think even if you eliminate all the pain in the world, that will stop all the people asking for euthanasia. The other group are people who have huge emotional sufferings. But those tend not to ask [for euthanasia or assisted suicide]; this is just my impression, I have not studied it. My impression is that people who suffer, [suffer] a lot emotionally whether it’s from guilt, regret or whatever. Physical pain will make all this come over all of us. And this is where the concept of total pain comes from. ...[E]ven if you eliminate the physical pain, everyone who dies is bound to suffer. Because you suffer from the loss of everything you know, that you’re familiar with—whether it’s a favourite material something, or whether it’s relationships or it’s a person. You still lose a lot of things—your sight, health, all these things. So losing these things causes us a lot of suffering. And of course the spiritual aspect would be, sort of, grasping for meaning, you know? Why am I suffering right now? People say that if you could find meaning for the suffering, then you could alleviate the suffering. I mean, if you know that you are suffering for that is your martyr(dom) or whatever, then it becomes worth it. You know why you’re dying, you know why you’re suffering. But most suffering seems pretty meaningless to people. [...] Some people want to short circuit that, don’t want to go through that. So they might also ask to end it all quickly.” (Doctor 70)

### 4.1 Doctors’ attitudes to Singapore laws in general

Many doctors did have a fairly good knowledge of medical law. However, they had a range of attitudes towards the law.

#### ■ The law’s perceived lack of relevance to good medical practice

Some doctors felt that medical law was not really relevant to good clinical practice.

“I actually fall into that group of doctors who prefer not to let lawyers tell us what to do. I think that rather than fall back on the law and say, “Oh! Is this legal? And blah blah blah,” we as a profession must get our hearts in order. We must do what we are supposed to do. And that is to make a clear assessment of what is going on, communicate properly with patients and families to find out what’s important to them and then together with them help guide them through the system. And help guide them to make the kinds of decisions that will best suit them. But I don’t think we are doing that well enough. And if we, I think if we were able to do at least that, we would solve a lot of the problems. It has nothing to do with law. And I don’t want to bring the law in because I think that once things have become entrenched in the legal framework, that doesn’t leave us room for flexibility and stuff like that.” (Doctor 13)

#### ■ Limits within which doctors work

Other doctors felt that the law was there in order to provide the limits of what doctors could do, so it was meant for doctors who transgress beyond the acceptable.

“I agree with the laws. I think the laws are a blunter instrument. It [the law] cannot be fine-tuned so much. It should only control the limits of human behaviour within which we should be able to function in a very big normality curve.” (Doctor 71)



## 4.2 Doctors' perceptions of the law relevant to consent and confidentiality

### ■ Perception that law and medical practice are at odds

It is not very surprising that many doctors do not think the law is very helpful or relevant to them with regard to consent and confidentiality.

“ Oh! Huge issues here, partly because 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. ” (Doctor 13)

### ■ The reality of clinical practice regarding consent and confidentiality

As discussed in the chapter on families, the clinical practice in Singapore tends to favour disclosure to the family before the patient, and decision-making for patients by or with the family. Most doctors did not seem to notice that this was in contradiction to the law in Singapore regarding consent and confidentiality. (Even in respect of incapacitated patients, the Mental Capacity Act requires that the individual is to be encouraged to participate as fully as possible in the act done or decision made.) Instead they tended to see their practice as different from 'Western' practices of prioritising autonomy.

“ I think if you talk to doctors, all the Singapore doctors would tell you, this is a constant day-to-day ground battle: the issue of non-disclosure and collusion, because it is non-disclosure and then they are asking you to collude with them not to tell. But we also realize that if we go in like a bull in a china shop, nobody wins. And everybody loses, including the patient. Because, after all, the patients are part of a family, and

what the family is doing is caring—what they perceive as the correct way of caring. So you really cannot go in like a bull in a china shop, using all your Western ideas of autonomy. That has to be thrown out of the window. You have to be very practical, and I say, “I’m not here to tell anything, I’m here to listen. So that shifts them, because they are very defensive. ” (Doctor 03)

## 4.3 Doctors' perceptions of the Mental Capacity Act and Advance Medical Directive Act

### ■ The Mental Capacity Act

Few doctors knew much about the Mental Capacity Act (MCA) or thought it was relevant to decisions at the end of life. Those who did know about it pointed out that the MCA did not actually enable proxy decision-makers to have any say in end-of-life decisions.

“ The proxy [decision-maker] cannot make the decisions but the doctors can. So in that sense it doesn't change how we have been practicing. I think the law must also take into account society and how society is changing. But the thing is, society is not represented by its more vocal members. So until you really know what it is like on the ground, you shouldn't rush to change the law. ” (Doctor 05)

They also reiterated that, in practice, doctors generally still involve families very closely in making decisions for incapacitated patients just as they do for patients who have capacity, rather than simply acting in their incapacitated patients' best interests as prescribed by the law.

“ I think if you are the thinking kind of doctor, you know that your duty of care is to the patient. I mean, the Singapore law follows the English common law. If the

## Law in Singapore relating to the end of life

*Terry SH Kaan & Tracy E Chan*

A survey of the current state of the law in Singapore will reveal a rather uneven landscape in which some bold new features have been superimposed on a general background of unchanging and enduring values inherited from the past, leaving some areas where there are legal uncertainties and gaps. Constitutionally, the Singapore legal system is a “common law system” modelled on England, from which we have inherited a lot of our laws; but since 1993, with the enactment of the Application of English Law Act, it is no longer automatically the case that English legal precedents apply in Singapore. The Parliament of Singapore has also enacted legislation such as the Mental Capacity Act and the Advance Medical Directive Act which apply to end of life situations in Singapore.

Valid, informed consent for an adult who is competent (that is, who is not incapacitated and has the ability to make treatment decisions) is the only legal consent for medical treatment. An adult patient is also the only person who can give consent for disclosure of his or her personal medical information, except in very specific situations such as communicable disease surveillance or child abuse where the protection of other people may make disclosure necessary.

Where a patient is not competent, doctors should act in the patient’s best interests, with the only exceptions being where the patient has made an ‘anticipatory decision’ by appointing another person with Lasting Power of Attorney (LPA) to be a decision-maker, or by signing an Advance Medical Directive (AMD) (see diagram on facing page). Even in these cases, the scope of both the LPA and AMD is limited and decisions will still need to be made by doctors. However, under the Mental Capacity Act’s Best Interests test, the relevant decision maker must consider the incapacitated patient’s (i) past and present wishes and feelings, particularly where these have been recorded at some point in writing; (ii) beliefs and values that would be likely to influence his or her decision if he or she had capacity; and (iii) any other factors that he or she would be likely to consider if he or she were able to do so. In order to realistically do this, the physician must consult, in particular, anyone expressly named by the patient, anyone engaged in the care of the patient, a donee of an LPA granted by the patient and/or a relevant court-appointed deputy. In Singapore law, therefore, 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.

The flowchart is organized into two main horizontal sections: **COMPETENCE** (top) and **INCOMPETENCE** (bottom), separated by a horizontal line.

**COMPETENCE Section:**

- Competent Adult Patient: Full Autonomy** (Green box): Competent adult patients have the right to choose between treatments offered, or to refuse treatment altogether, choosing the natural course of the disease (but may not commit suicide).

**INCOMPETENCE Section:**

- Incompetent/Unconscious Adult** (Grey box): This is the starting point for the incompetent section.
- With Anticipatory Decision: Extended Autonomy** (Teal box): Autonomy principle requires that anticipatory decisions made in advance of incompetence are to be respected and acted upon in the same way as if the patient was still conscious and competent.
  - It leads to the **Advance Medical Directive Act** (Teal box): Statutory "living will" executed pursuant to the Advance Medical Act—healthcare givers must comply, but note restrictive trigger conditions (must be unconscious or incompetent, and suffering from terminal illness, and requiring extraordinary life sustaining treatment if life is to be maintained).
  - It leads to the **Mental Capacity Act** (Light Green box): Lasting power of attorney under Part IV of the Mental Capacity Act—note restrictions in s8, s13 on acts in connection with care and treatment, and end of life.
  - It leads to the **Common Law Anticipatory Decision/Directive ("Living Will")** (Yellow box): Extent of applicability of English common law principles in Singapore untested, but note s12 & s13 of Advance Medical Directive Act.
- Statutory "Best Interests" Principles** (Light Green box): Parts II & III, The Mental Capacity Act.
  - It receives input from the **Advance Medical Directive Act** and the **Mental Capacity Act** via dotted lines.
  - It is linked by a double-headed arrow to the **Common law "Best Interests" Test** (Orange box).
- Common law "Best Interests" Test** (Orange box):
  - It is linked by a double-headed arrow to the **Medical Futility** (Orange box).
  - It leads to the **No Anticipatory Decision** (Yellow box) via a solid orange arrow.
  - It leads to the **Death** box via a dotted red arrow.
- Medical Futility** (Orange box):
  - It leads to the **No Anticipatory Decision** box via a solid orange arrow.
  - It leads to the **Death** box via a dotted red arrow.
- No Anticipatory Decision** (Yellow box):
  - It leads to the **Death** box via a solid orange arrow.
  - It leads to the **Statutory "Best Interests" Principles** box via a solid orange arrow.
- Death** (Red box): Statutorily defined by Section 2A of the Interpretation Act: either "irreversible cessation of circulation of blood and respiration" or "total and irreversible cessation of all functions of the brain".
  - It receives input from the **Advance Medical Directive Act**, **Mental Capacity Act**, **Common Law Anticipatory Decision/Directive**, **Common law "Best Interests" Test**, and **Medical Futility** via dotted red arrows.
  - A note at the bottom left states: *Persistent Vegetative State: Requires Order of Court*, with a dotted red arrow pointing to the **Death** box.

© Terry Koon, 2011

patient is incapacitated, has no mental capacity for decision making and has not named a proxy, actually it is the attending physician who should be the one to make a decision in the best interest of the patient. Of course, best interests can...[does not finish thought] there is a whole seminar on best interests, I am sure you can get one whole interview on that. But most doctors know their duty of care, and that they should be the one making the decision in the best interests of the patient. In reality, it doesn't happen on the ground. In reality they always involve the family. But I think it is right, because in the Asian context, the patient is part of the family unit, and there is a lot of collective autonomy and collective decision-making. Even when the patient is mentally capable, most patients do have the collective decision-making with the family [embedded] in culture. So it's probably not wise in our culture for the doctor to say, "Since you have no mental capacity and you have not named a proxy, I will take over decision-making." That won't be right. You really have to bring them in and first find out whether he has made a written will or advanced directive [somewhere] hidden away. And, secondly, to find out what the patient has discussed with his family. There's a chance that the patient would have said to them what he wants before he was mentally incompetent. And try to figure out what he would have wanted. ” (Doctor 03)

This is an incomplete understanding of the newly enacted statutory best interests test—Section 6 of the Mental Capacity Act does not prescribe a medical best interests test, but one tailored to the values, preferences and wishes of the particular patient. So it seems that clinical practice and the law might have moved closer to each other than realised. The model articulated in the quote above offers a collaborative model of decision-making that fits quite well into the framework stipulated by the MCA. However, the MCA is quite clear that the

focus must be on what the incapacitated patient would have wanted, and not what the family members think is best for the patient.

### ■ The 'two consultants' rule for doctors making decisions in the patient's best interests

Some institutions in Singapore had a different way of dealing with consent—when patients were incapacitated, the policy was for two senior doctors to make decisions for these patients in their best interests, with variable levels of consultation with families.<sup>1</sup> In so far as there are no family or friends to consult, this may be the only practicable alternative.

“What I'm very impressed with [at] the Department of [names department] there is that they don't get consent from the family in general. And, what they do is, they use the 'two consultants' rule. They've actually got a form for two consultants and everyday I'm signing one of those forms. Because they recognize that the law says the doctor must act in the best interests of the patient. So the patient doesn't make the decision; there are one or two who are wards of the state, so we call the legal guardian. And if not, these are people who are from the destitute homes, the [names institution]. And there's an administrator who's been appointed as the legal guardian for this person. If not, you just get two consultants to sign the form. And this is the only hospital in Singapore that has, as far as I know, made that a practice. All the others get consent from the families.”

Interviewer: Which actually has no legal standing?

“No legal standing at all. Anyway, especially if you've got a big family and you've got somebody who signed, and somebody else says, "How could my brother sign?" Then what do you do?"

Interviewer: So, can I follow that up? The two consultants rule, and how do they deal

with the family at [hospital name].

“Yeah, so what they do is they tell the family: this is the procedure that needs to be done, it’s heavily subsidized. First thing the family want to know is how much it will cost. So you tell them it is not going to cost that much, and all the doctors had agreed that this needs to be done.” (Doctor 60)

### ■ Advance Medical Directives

The Advance Medical Directive (AMD) Act was well known to doctors, some of whom thought it was a very good idea in principle.

“...[For instance] the whole gang of people who came to my clinic asking for the AMD, they didn’t think that the government was saving money. Their thought was, “If I were to die, I don’t want to burden my family.” That was their main idea. They were thinking, “If I want to die old and I’m not going to live very long [at that stage] despite everything everyone is going to do, I’m not going to live, that is, I’d want to die. I don’t want to burden my family with costs.” They don’t seem to be able to tell their children directly, “Don’t do everything for me when I am about to die.” (Doctor 34)

### ■ The limitations of the Advance Medical Directive Act

The AMD was, however, seen by those very conversant with its terms as highly problematic for several reasons. First, doctors were aware of the low uptake of the AMD; so few patients at the end of life would have previously signed an AMD. Second, the doctors pointed out that they were forbidden by law to ask a patient whether they had signed an AMD, which made it unfeasible in an emergency or crisis to determine whether one was in place. Finally, doctors correctly pointed out that the AMD was very stringent and its use is restricted only to situations where the patient is effectively already dying

and the only question is whether or not extraordinary life-sustaining treatment ought be continued. This meant that most end of life decisions were not covered by the patient’s wishes as expressed in the AMD.

“AMD, unfortunately, will be applicable to only a very, very small segment of our patients. The AMD—if you look at the way our AMD is crafted, you get the feeling it was crafted because there was growing fear among the population that, even when I am dying, my stupid doctors would want to continue treating me, as though I am not dying. Therefore I am declaring beforehand that, when you know I’m dying, I give you permission to stop.” That’s the aim. Because it’s so stringent.” (Doctor 01)

“I think they are revamping the AMD Act. They are re-looking into that. Because the take-up is very poor and they think perhaps it was framed too rigidly. And the process is difficult. In the A and E, you have to resuscitate first, right? You have to resuscitate, give the benefit of the doubt and resuscitate. And then, you have to, you have to find out if the patient has an Advance Medical Directive and not all the time the relatives know. Then you have to go and apply, to call up the office to see whether they have. And then even if they have an Advance Directive, you are supposed to verify it, to show you, even if they say they have an advance directive you have to verify it. And they have also limited it, very limited.”

Interviewer: Very stringent, almost to the point of death!

“Yeah, very stringent, even an amah sweeping the road can see—no need for an advance directive!” (Doctor 03)

Another problem raised was the problem of stability of wishes for the future—that people might make an AMD when they feel depressed, or worry about burdening

others; and also that people often changed their minds towards the end of life. There was a further concern that having an AMD might mean that treatment is withheld against their wishes if they change their minds but are unable to express themselves.

“...once a patient gets labelled DNR (Do Not Resuscitate), then the nurses here don’t do anything for this patient. And I had asked the MO [medical officer] as well as the nurses. I had an AMD when I was in [names American city]. When I was in [American city] I signed something. I said I did not want to be sustained when I’m hospitalised. So I said, “If I come into hospital and I get a fish bone [in my throat], are you going to resuscitate me?” He [the MO] said “No”. I said, “What?” [Everyone laughs.] I said, “I’m not going to die from a fish bone getting stuck in my throat!”” (Doctor 60)

#### 4.4 Doctors’ attitudes to withholding and withdrawing treatment

##### ■ The moral acceptability of withholding and withdrawing treatment at the end of life

Doctors generally had no problems with the concept of withholding and withdrawing treatment from patients, when treatment was futile and unlikely to help the patient. Many doctors pointed out that modern medicine has developed to the point where a multitude of treatments could increase suffering in return for no real gain for the dying patient. In such situations, doctors felt that withholding such futile treatments was morally permissible.<sup>2</sup>

“Withholding means that we are letting the disease go natural, basically not altering the nature of the condition. If you see it like this—that in the past certain diseases

were incurable, and now become curable—if we withdraw treatment due to its being no longer useful, or because the patient also has the autonomy to say, “I don’t want it anymore,” I think I am fine with that. We let the disease run on its own, [and it is] still not against nature. But if we do something to speed up the progression of the disease, say, towards the patient’s death, I think it’s not right.” (Doctor 06)

##### ■ The emotional difficulty of withdrawing treatment at the end of life

With some exceptions, most doctors felt that withdrawing futile treatment was morally the same as withholding treatment. However, several of them found that in practice, withdrawing treatment that had already been started was often very much more difficult than withholding it in the first place.

“For me, I think that definitely withdrawal is more difficult emotionally, based on past experience. I want to share about this young [names ethnicity] man, 40+, who had advanced [names type of cancer] with mets [metastases] to the lungs, very bad perfusion, so he came in very breathless. The cardiothoracic surgeon said, “I’ll go in. I’ll do what I can. I will remove whatever I can.” Post-operatively, he was intubated, couldn’t be weaned [i.e. off the ventilator], but he was alert enough to say, “This is not what I want. I want it removed, I want to go home and die.” So, it becomes a withdrawal of treatment here. And actually bringing him home and physically removing the tube, and seeing him die in front of me, was very...[pauses] quite tough. Very difficult.”

Interviewer: Wow! So you brought him home on a ventilator?

“On a ventilator. So when we reached home, we actually removed the tube. He was able to look around. We prepared morphine to make him comfortable, and



in a few minutes, he passed on. I find that, emotionally, that is very difficult. Up to this point, sometimes, I do ask myself, “Would I have done it again? Would I have done it this way, versus not even putting in the tube?” It [the latter] would have been easier. So, morally, I think that one, for me, personally, I think it is more difficult to withdraw. It is better to come in from [inaudible], you can foresee what is down the road, rather than end up having to withdraw.” (Doctor 63)

#### ■ The emotional difficulty of withholding and withdrawing food and water at the end of life

Withholding and withdrawing hydration and nutrition (that is, food and water), however, proved much more difficult, morally and emotionally, for some doctors. This was because feeding signified to some care and the meeting of basic human needs, even when it had to be delivered through tubes. It also had a strong emotional significance to most people, both family members and doctors themselves.

“And I think that is the way a lot of families look at it as well. Withholding and withdrawing (nutrition and hydration) is withdrawing care, caring for our patients.” (Doctor 25)

“I think from a physician’s point of view as well. A lot of physicians are uncomfortable not feeding any one of their patients. So a lot of patients maintain their liquid up till the end. Because we feel like something to drink is almost like giving our care to the patient.” (Doctor 29)

“To some extent some physicians feel that it’s the last thing they have to offer.” (Doctor 26)

## 4.5 On suicide, euthanasia and physician-assisted suicide

### ■ The moral unacceptability of hastening death

In contrast to consent, confidentiality and the MCA and AMD, where doctors tended to have few strong feelings, there was very strong feeling about the subjects of euthanasia and physician-assisted suicide. The doctors we interviewed were universally against the idea of euthanasia or physician-assisted suicide being readily available options in law if doctors were in the role of the person delivering the means for ending the patient’s life. Most of the doctors were strongly against anyone being allowed to actively hasten death in patients, whether the patient was in terminal stages of illness or not.

“And I am against the idea that we do something actively to hasten death. OK, that to me is the definition of euthanasia—that you actively do something to cause the patient to die. You actually do something to have a biological death. And it’s my personal belief, whether religious or philosoph(ical), that it should not be done because life and death are not in our hands.” (Doctor 14)

### ■ The minority view in favour of decriminalising suicide at the end of life

The current legal position in Singapore is that an attempt at suicide of a person and the abetment of suicide of someone else (that is, helping someone else commit suicide) are both criminal offences in Singapore. In England, the former is no longer an offence but the latter remains so. A few of the doctors wondered whether Singapore should allow people the right to commit suicide, if they had specific types of terminal disorders which caused a lot of suffering. But, with one exception, even these doctors were clear that it was not

appropriate for doctors to have a role in this act of suicide.

“The patient has to initiate it. We cannot create a disease and argue about it. The patient has to bring it up. And when the patient brings it up, ‘I am suffering from a terminal disease. I want to execute this’. So [then] the law says, ok, if you’ve got two medical practitioners who can certify that you are suffering from a terminal disease, here you are [and you can proceed to end your own life]. That’s all.” (Doctor 12)

“I can think of a few occasions where I have been quite caught in a quandary of this person being actually, for the lack of a better term, a ‘rational suicide’. They will say that, yes, you know, and they will tell you this 慘 [Hokkien, translation: tragic] story that will... that sounds even more 慘 than the Channel 8 [local Chinese television channel] serial, and the South Korean series. At the end of the interview, the fellow will calmly tell you all of these things; and I would actually tell myself that, actually, it is grounds for rational suicide, but of course I won’t facilitate that. I can think of one particular case where that fellow actually did complete the suicide. Not under my watch, but actually it was the subsequent admission. He actually jumped from the hospital. And, seemingly, to the staff and all, he was actually quite calm and almost happy. But he took a very clear decision that [it was] mainly for so-called financial reasons that, ‘I no longer, on the one hand, want to put the burden on my family and, on the other hand, I don’t want to go through anymore of this suffering.’ You tell him one month, three months, six months, to him, it’s very rational. ‘Why bother? I’ve got nothing else to live for already. My family are ungrateful and not around me. I’m totally alone.’” (Doctor 13)

## ■ Acceptance of the Doctrine of Double Effect

The doctors were almost all aware of the ‘Doctrine of Double Effect’—the principle that giving someone treatment to alleviate suffering may hasten death, but that this was acceptable so long as the intent was to relieve suffering rather than to hasten death. They agreed with this doctrine and saw a clear moral distinction based on intent.

“But I think if you happen to incidentally hasten death, as a by-product of trying to relieve the suffering, and limit the suffering like we do [with] morphine, for example, then that’s different. Your primary objective is to [pauses]... again it comes back to the thing, respect the person, respect the individual, his life. Respect the fact that a lot of medical procedures are really, really darn painful. It’s really terrible to be intubated and to be tied [spread]eagled like that. I mean, it’s horrible. So respect the fact that technology does not equal to good, [or] does not equal to no pain. If anything, it can be more painful. So once it’s down to that, to me, it’s okay.” (Doctor 06)

“So, yes, I think it is how active we are. So you can argue that giving as much morphine as the patient wants—to the point of potentially the double effect type of argument—I would still say that, yeah, you know, I would still put an emphasis on comfort, even if that’s the double effect. But I wouldn’t quite go as far as to purposefully give, say, you know, a lethal dose of KCl [potassium chloride: this would stop the heart] or whatever lah, for that specific purpose. So, no hemlock [ancient drug taken to commit suicide] for me.” (Doctor 13)

## ■ Reasons for opposing physician-assisted suicide and euthanasia

There were several distinct reasons for the doctors’ opposition to physician-assisted

suicide and euthanasia.

The **first** reason, most commonly voiced, was that Singapore society is not ready for that sort of legislation.

“I am a traditionalist when it comes to non-suicide and non-euthanasia, and non-assisted suicide kind of legislations, so I think that Singapore is probably not ready for that kind of legislation, à la [names several countries] and their kinds of legislations.” (Doctor 13)

“Even though it’s a continuum, and you do all this, the fact that you actually shoot something in and kill off someone, especially if that person is still very alert, I think that’s still [pauses]...I don’t think they’re ready anyway. I’m not saying it’s a good or bad thing. I’m not judging the rightness or wrongness because maybe countries that have brought in euthanasia laws have very good reasons to do so; or the community is mature enough to think about these things. We are not even at the stage of writing our own wills for goodness sakes, you know? We’re way down here.” (Doctor 06)

A **second** reason was that to ask for assisted suicide or euthanasia meant that patients were desperate and suffering; and many doctors felt the solution was not to provide for assisted suicide or euthanasia, but to improve palliative care and avoid needless suffering in patients.

“And really the general sentiments of the community are that we’re not ready for physician-assisted suicide, let alone euthanasia. Totally, totally not ready for this. So it will not be discussed. The law is not going to change anytime soon.”

Interviewer: But what are your views on it?

“I disagree with that. I disagree with both. I think that the whole debate [pauses]... 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.” (Doctor 11)

“So I think that before we embark on this [physician-assisted suicide and euthanasia], like I said, they need to get the basics right. We shouldn’t be talking about this as a first option when what is preventable, is prevented, and whatever suffering can be relieved, is relieved; because there are better ways to relieve suffering than to remove the sufferer and, unfortunately, I worry that people will see that as a more straightforward and easy way out.” (Doctor 05)

A **third** reason for opposition to physician-assisted suicide and euthanasia was that this infringed on the doctor’s role, and doctors were very uncomfortable about doctors’ powers being extended to include hastening death. A **fourth** reason was that a request to end one’s life required an act by someone else, so it could be an infringement of the doctor’s personal rights to insist on this.

“Well, I would... I would actually be quite open with patients whom I know quite well; you know, I might even say things like, you know... “I can understand why you feel this particular way”. But, say, if they were to request—as often they do—to say that, you know, “can you give me something to end my life?” then I’ll say that, unfortunately, that’s not what doctors do. We are in the job of preserving life and/or to maintain

comfort even when life can no longer be prolonged in that sense... and it goes counter to what I am allowed and trained to do.” (Doctor 13)

“So I think that one of the differences between this [a law allowing physician-assisted suicide and euthanasia] and, let’s say, the attempted suicide law, is that this kind of law—where there’d be an act(ion) [of] physicians to assist in suicide or euthanasia—inevitably involves someone else, and that someone else is a member of the profession. So it is not this so-called prize, or autonomy and all that sort of stuff. Autonomy does not exist in a vacuum. The moment you exercise yours, you bump up against someone else’s, and that has to be taken into account. You know, you cannot have autonomy without restriction. That would be anarchy. And I think all these people [pauses]... some of the most strident calls, I feel, sometimes miss that part of the big picture. It’s not just me, me, me.”

Interviewer: Do you think if... I’m trying to understand this... Are you saying that no one has the right to ask someone else to do [interrupted]

“No, you have every right to ask someone else to do it, but you don’t have the right to expect that society will sanction it in law.” (Doctor 05)

“[I]f the patient, like, does something [that] infringes on my right—like, “I want you to kill me,”—then, for myself, I wouldn’t kill you, I wouldn’t respect your autonomy.” (Doctor 09)

A **fifth** reason to reject a change in the law to allow euthanasia or physician-assisted suicide was that, although there might be a small group of vocal, independent patients who may benefit from this, there would be many more vulnerable patients who may suffer from abuse of a law allowing euthanasia.

“Why should we change the law? Changing the law is not such an easy thing, is it? Because every time we do something it has social impact. [...] Well, well I want, not just to relieve suffering. I want to protect the vulnerable. I want to give people the reassurance that they will not be pressurised into taking the easy way out. And people are not just the patients, but also the doctors. And therefore I think that before we talk about a law like this, we as a society, need to be mature enough to actually have a reasoned, rational discussion about death, about dying, about illness, about suffering, about end of life, and we haven’t done that.”

Interviewer: Because...sorry, I made you pause... I kind of connected that back to what we were talking about—about families, and how we were saying, when the family’s interests do come before the patient’s interests. That’s of course relevant because in the euthanasia debate in the West, there’s always this assumption that the person asking for it is fully autonomous and can make up their own minds but, of course, in family systems—where it is much less clear, when we’re getting into very muddy, very deep, waters about who the request is coming from—what does it reflect? And, of course, these people who are vocal are not really very vulnerable. The vulnerable are not necessarily...

“They’re the quiet ones. Or even the ones who are not able to speak at all. I still remember—a few years ago—there was this big brouhaha about euthanasia and all that. I kept a lot of newspaper cuttings, and I remember this letter that came out in the forum about somebody who was saying—I think their mother-in-law or somebody who had been bed-ridden for ten years, twenty years, you know—“So terrible! What a life that is. You know, if I had known about this euthanasia thing, I would have asked it for her a long time ago.” (Doctor 05)

A **final** reason, which most doctors spoke about, was that their personal beliefs did not allow them to hasten death through their actions. Many of these beliefs were strongly rooted in their religious faith and personal value systems.

“Interviewer: What do you think of suicide, physician-assisted suicide and euthanasia?”

“I’m actually against it. The prime reason is that I’m a Christian and am against such things naturally. If you asked me, if active euthanasia became legal, I would still not carry it out. I would still not do it.” (Doctor 16)

“I think it’s hard for me, given my background as a Christian, and given my experience as a physician, I think it’s really hard to help someone die. I think to an extent we try still to alleviate discomfort with treatment, rather than this; and if the person still refuses further active treatment, we will pass on from that. I think for us, we are more comfortable in those aspects. Sometimes we do understand, and we do empathise that pain can be excruciating. But where pain gets so excruciating to the point of the patient actually request(ing) assisted suicide, what can be done [is that] we would still help the patient by giving him some kinds of treatment. Sometimes the treatment may not cure the patient but it will knock him out.”

Interviewer: That’s the doctrine of double effect.

“That’s right.”

Interviewer: The intention is not to kill.

“That’s right. It’s not to do that, but if in the course of it, the patient is demised, then that’s ok. That, to me, is more acceptable than demonstrating empathy through assisted suicide.” (Doctor 02)

“I think there is a big difference. If you hasten death, it means you actively do something towards it. I don’t think

the Muslim [would] do it, you know, it is probably criminal to do that. I don’t think they [would] allow that, but if you are talking about withdrawing of treatment and all that, it is very commonly done. Among the Muslims, it is something that has been done all along. They just don’t send the patient to the hospital. That is something that we always face. In fact, often we are called for house calls, and the question is, “Do you think we need to send [the patient] to hospital? Is she going to die? If she is going to die, we [will] just let her die, or die at home”. ” (Doctor 68)

“So, as I mentioned just now for Buddhists, if you die with an unwholesome mind, that’s a mind [with] either aversion, or greed, [that is,] attachment. Aversion can take many forms. Worry is aversion. Fear is aversion. Hatred is aversion. Anger is aversion. Then greed is attachment, clinging, not wanting to leave. So these are unwholesome mind states. If you die in that unwholesome mind state, you will be reborn in an unpleasant place, in a situation. In Buddhism also we believe in the existence of hell, a ghostly realm where they hang around. They do not want to go [there], you know. [...] So if somebody were to commit suicide, necessarily, there is an unwholesome mind. [...] Yes that’s out of hatred, that you kill yourself. Then you’d probably end up in a woeful plane. And if you’re in [a] woeful plane, it’s not easy to come up to a better plane. So suicide is not a good death. [...] And then killing, it’s not a good mind state for the person doing that. Like, you may think of what is good for the patient, you know, maybe, relieve the suffering. But when you actually do that, necessarily have that idea that this suffering is disgusting. I hate it.”

Interviewer: Ahh. Yes. So you must be agreeing with your patient that it’s unbearable, intolerable, in some way?

“Yeah. And averse to it. Then it’s not good for the doctor to do that. So I won’t kill for



myself you know. It's because of me that I won't do that. And I won't recommend other people to do that because it's not good for [them]. Because morality in [the] Buddhist religion is related to [the] law of karma. Because it's not good for your karma to do that, so I wouldn't agree to suicide or killing, and so on. But whether it is a law or not, I mean, it's beyond me. I don't know whether it is better [for there] to be a law or not a law. ” (Doctor 09)

### ■ Exceptions for special cases? Potential problems

Although none of the doctors interviewed approved of euthanasia or assisted suicide in general, several of them had some reservations about particular and troubling cases where they had seen patients near the end of their lives in extreme suffering and wondered if it should be permitted in such special cases. The problem was: who could do it?

“ But there's a certain small group [of conditions], motor neuron disease, for example. What can you do to it? The more you support, the longer the patient suffers. They are going to die anyway. What are we trying to achieve? While you ignore it, the other thing [that worries you] is financial sustainability. The population is now fairly young. If you are rich you can still support it. But when you become an ageing population, twenty percent are above sixty-five to seventy years old. You're financially not sustainable anymore. When it comes to that, is it worthwhile to carry on anymore? Are we able to do anymore for these patients? And is it cruel to terminate lives? If I try to imagine myself in the patient's shoes, I probably would have made the same decision. And I really wish there was euthanasia around to settle the problem; otherwise it would be a big burden to the family and to everyone else. And you yourself would be suffering. Imagine that you're here mentally alert, trying to

communicate and you can't do anything, [plus] being bedridden the whole day. It's terrible. If you're comatose, it's easier. This isn't even comatose. I find that at the end, assisted suicide is not for everyone. But when it comes to this small group of people, unfortunately if the doctors say that with the current science and technology, there's no cure, we shouldn't prolong the patient's suffering. That comes back to my principle that, if you can't cure, don't prolong suffering. And for this we are not forcing everyone to go for it. Again, autonomy will come in. The patient has to make the call to terminate their own life. ” (Doctor 39)

“ I think you need the Euthanasia Act partly because I don't think it's fair for relatives or anyone else to truly do this on the patient. How do I put this? I don't want relatives to remember this for the rest of their lives that they did this.”

Interviewer: So physicians should be the ones to carry this out?

“Yes, and it shouldn't be the physician who'd been in charge of the patient but someone else.”

Interviewer: Ah, a different physician?

“Yes. Because I think the physician that had been looking after the patient would have ties with him. It would be difficult for the personal physician. Then you'll find that physicians wouldn't take part in the whole act. If you think further, it's not really fair to the patients or their relatives. ” (Doctor 20)

At the same time, some doctors worried that if exceptions were allowed, then it would become very difficult to judge between the special cases that merited euthanasia and assisted suicide, and those that do not; and that this may be opening the door to potential abuse.

“ I can understand if someone is under severe excruciating pain and they clearly want it, and they are *compos mentis* [Latin:



of sound mind]. I might not accede to their request, but [pauses]... There are so many “what if’s”: what if he wasn’t thinking straight, what if he was depressed. I would never feel comfortable enough to say that. So I don’t want to go down that slippery slope. ” (Doctor 43)

“ Um, okay. I think the laws should stay as they are. We should not legalise active euthanasia. The reason is, I think that if you open this up, people might abuse it. That’s my worry.”

Interviewer: Okay. In what ways? What do you mean by abuse?

“In a way, um, well, I’ve never encountered any such situation but this is what I

can think of. Suppose a patient may be so-called terminal, or may not be even terminal, honestly, but is simply sick of his illness and wants to end his life. Then requesting a medical person to execute the suicidal act on this person—I think if it becomes legal—it actually becomes equal to suicide. I don’t think there is a difference. If we legalise it, we could shift the story and say this person has a cancer. We don’t have to tell the lawyer which cancer it is, the person may be able to last two or three years, the cancer is not that terminal. But because this person doesn’t want to live with the cancer, and asked me, I did it. We can sort of twist the story. ” (Doctor 16)

---

### Summary

Doctors generally see the law as setting the boundaries for their practice, and do not seem to notice discrepancies between their clinical practice and the Singapore law that governs adult consent and confidentiality. They see very distinct moral differences between withholding and withdrawing treatment and hastening death—the former is morally acceptable to most, and the latter morally unacceptable to almost all. Withholding and withdrawing treatment is seen as morally acceptable in cases of futility or competent patient refusal, but withholding and withdrawing nutrition and hydration is much more ambivalently viewed. Euthanasia and physician-assisted suicide is largely disapproved of and most doctors do not want their profession to have any part in such acts, though many specific cases of severe suffering do trouble doctors.

---

# CONCLUSION



**D**octors have a lot to tell us about the needs of patients at the end of life and their families, and the care of the dying in Singapore. This project has attempted to provide a glimpse of the complexity of the issues involved. This report demonstrates the importance of the local context in many aspects—how families support and care for each other, how religious and personal beliefs shape attitudes and perceptions, how the health provision and payment systems are structured, and how the law in Singapore affects doctors and the provision of care. These all interact to create challenges for doctors who care for patients at the end of life.

Because of its brevity, this report cannot begin to capture the richness and complexity of what the doctors said to us. Furthermore, it is not the role of this type of research to provide definitive answers to questions about how the care of the dying and those nearing the end of life in Singapore can be improved. It is our hope that by opening up a window to the world of doctors working in this area, we will provide some data that can be the basis of an open, stimulating and wide-ranging debate in the public domain on this subject. We hope that this will pave the way for improvements in all matters that contribute to the care and wellbeing of patients at the end of life and their families, which reflect the values and needs of the people of Singapore.

# ENDNOTES

## Executive Summary

- 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.

## Introduction

- 1 The different types of healthcare in Singapore will be explained in Chapter 3.

## Chapter 2 The Role of the Family

- 1 'Assent' is the legal term for the patient's agreement to treatment when the patient is not the legal decision maker, for example, because parental consent is sought for a legal minor, or when an adult patient does not possess the ability to give informed consent.
- 2 Medisave is the Singapore national compulsory healthcare savings scheme which all employed Singapore citizens and Permanent Residents are enrolled in. Under the scheme, a proportion of their earnings are placed in a personal account earmarked for medical costs. An individual can use his Medisave to pay for his own and his immediate family members' hospitalization, day surgery and certain outpatient treatment expenses, but this finite resource can be exhausted.
- 3 Medifund is an endowment fund set up by the Government to help needy Singapore citizens who are unable to pay their medical expenses. This is a safety net for those who are unable to afford the subsidized charges at restructured hospitals even with their Medisave and the use of MediShield (a catastrophic medical insurance scheme to help individuals meet the cost of medical treatment, but only for serious illnesses or

prolonged hospitalisations at Class B2 or C wards).

## Chapter 3 Healthcare for the Dying in Singapore

- 1 Private general practices generally consist of GP clinics located in housing estates or near workplaces. There are about 2000 private medical clinics providing about 80% of primary health care. Private primary health care in Singapore is generally not subsidised by the government, but some government subsidised schemes are available, such as the Primary Care Partnership Scheme for the needy which enlists the participation of GPs. Patients must be means-tested to qualify for these subsidies, and GPs undergo a somewhat onerous application process to get on board the scheme and recover the subsidy. For a number chronic illnesses, the Chronic Disease Management Programme allows the use of Medisave for outpatient care, subject to co-payments and caps per year on amounts drawn from each Medisave account within the immediate family.
- 2 Private hospitals and specialist practices provide unsubsidised acute and specialist outpatient care for patients who can afford premium health care service, paid for by patients out-of-pocket, or through private insurance, or Medisave (if the institution has registered to participate in the Medisave scheme).
- 3 Polyclinics are outpatient treatment centres that also provide a range of primary care services including immunisation and health screening, and investigative and pharmacy services, but not house visits. They are located in major government housing estates and account for about 20% of primary health care. Polyclinic health services are heavily subsidised by the government, and remain highly affordable and available to all citizens but, for this reason, services are severely stretched.

- 4 'Restructured' hospitals are acute hospitals with associated outpatient specialist care services that are privatized, but care is tiered into 'Classes A, B1, B2 and C' with substantial subsidies from the government for Classes B2 and C. The public healthcare system of 8 acute care hospitals and 8 national specialty centres is currently organised within 5 broad clusters, for integration with polyclinics, community hospitals and outpatient specialist care facilities.
- 5 Community-based healthcare services provide day-care and home-care services for terminally ill patients, or those with chronic illnesses, who wish to be cared for 'in place'. Residential care is available at community hospitals, chronic sick hospitals, nursing homes, inpatient hospices. These services are managed either by Voluntary Welfare Organisations (VWOs) with subsidies paid by the government, or by private operators, who generally attract no subsidies. Patients are charged fees which may, in subsidised

services, be tiered by class of care. Needy patients at MOH-funded residential and non-residential facilities may apply for subsidies through means testing; and Medisave accounts may be drawn upon for care at these institutions, if they are on a registered list.

## **Chapter 4**

### **Law and the End of Life**

- 1 Although authority can rest with the person administering treatment, the Mental Capacity Act requires that relevant family members be consulted, and not just be told what has been decided.
- 2 Unlike in jurisdictions such as England or Hong Kong, there is no published guidance in Singapore setting out the circumstances in which the end stage of medical futility may be inferred that could be made available to doctors, patients and their families.

# RESOURCES

For further information on selected topics, the following may be useful:

## **Published Reports about End-Of-Life Care in Singapore**

The Quality of Death: Ranking end-of-life care across the world (2010) Economist Intelligence Unit: <http://www.lienfoundation.org/pdf/publications/qod.index.pdf>

Koh Buck Song, Living with the end in mind: a study of how to increase the quality of death in Singapore (2011) Lien Foundation, Singapore. [http://www.lienfoundation.org/pdf/publications/living\\_with\\_the\\_end\\_in\\_mind.pdf](http://www.lienfoundation.org/pdf/publications/living_with_the_end_in_mind.pdf)

## **The Healthcare System in Singapore**

Health care system, facilities, and healthcare financing information from the Ministry of Health website: <http://www.moh.gov.sg/mohcorp/hcssystem.aspx?id=102>

Information on current integration of intermediate and long-term care: <http://www.aic.sg/>

Information about Medisave, MediShield and MediFund: <http://mycpf.cpf.gov.sg/CPF>

Information about hospice care: <http://www.singaporehospice.org.sg/index.htm>

## **The End-Of-Life Legislative Framework in Singapore**

Statutory legislation: <http://statutes.agc.gov.sg/> including

- a. s2A Interpretation Act (definition of death)
- b. Human Organ Transplant Act (application of brain death definition)
- c. Medical (Therapy, Research and Education) Act (application of brain death definition)
- d. Advance Medical Directive Act (living wills)
- e. Mental Capacity Act (proxy decision making)

## **Academic Publications**

Singapore's Ageing Population: Managing Healthcare and End-of-Life Decisions (Ed) Wing-Cheong Chan (25th May 2011) Routledge Contemporary Southeast Asia Series. Hardback: 224 pages. See Chapters by:

Kaan, Terry SH, Shifting landscapes: law and the end of life in Singapore

Chan, Tracey E, The elderly patient and the healthcare decision-making framework in Singapore

# APPENDIX

## The Research Team

This research has been carried out by Assistant Professor Jacqueline Chin and Dr Jacinta Tan, Senior Visiting Research Fellow, Centre for Biomedical Ethics at the National University of Singapore. Jacqueline is a philosopher and ethicist; Jacinta is an empirical ethics researcher who has backgrounds in sociology, philosophy, psychology and child health and is also a medically-qualified child and adolescent psychiatrist. Jacqueline and Jacinta have joint responsibility for the authorship of this Report. The research team also includes two academic medical lawyers, Associate Professor Terry Kaan and Assistant Professor Tracey Evans Chan of the Faculty of Law, NUS, and Professor Alastair V Campbell, Director, Centre for Biomedical Ethics. Miss Luo Zhi Fei rendered excellent research assistance.

## What We Did

### ■ The Interviews

A total of seventy-eight doctors working in a range of settings in Singapore were recruited, mostly consultants or doctors who had completed training and some advanced specialty trainees (qualified doctors training to be consultant specialists). They came from a range of disciplines to reflect the diversity of types of medical practice in Singapore: general practitioners, paediatricians, physicians (haematology-oncology, infectious diseases, neurology, renal medicine, rheumatology, internal medicine, gastroenterology), surgeons (paediatric surgery, general surgery, hand surgery, breast surgery), palliative care physicians, geriatricians, psychiatrists, obstetricians and gynaecologists, emergency medicine physicians, intensive care physicians and anaesthetists, public health physicians and epidemiologists. Efforts were also made to recruit doctors from a range of work settings: specialist restructured institutions, private specialist practice, polyclinics and private general practice, hospices, community hospitals,

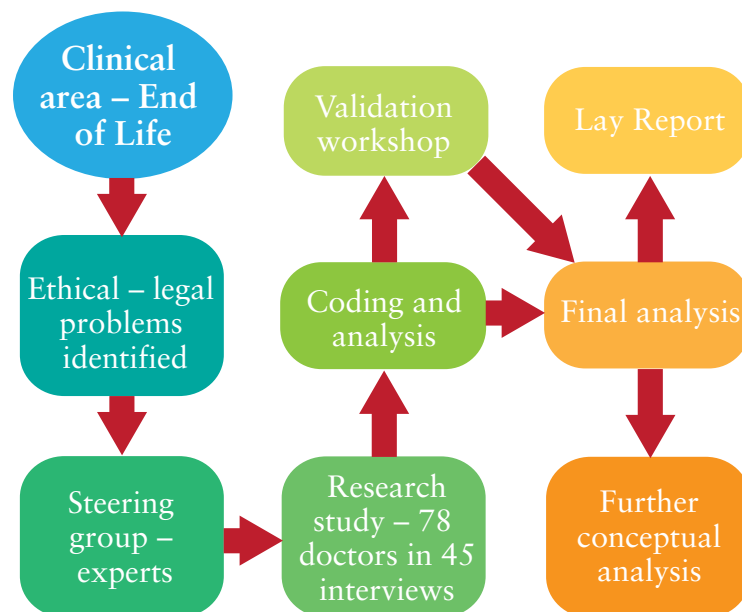
home-based care and academic medicine.

Forty of the doctors were interviewed individually, and the rest were interviewed in groups ranging from two to fifteen individuals; a total of seventy-eight doctors were interviewed in a forty-five interview sessions. Each interview lasted between sixty and ninety minutes, and was tape-recorded with the participants' knowledge and consent. The interviews were carried out using a Topic Guide to assist the researchers in covering the main subjects under enquiry, but emphasis was placed in the interviews on conducting an exploratory dialogue to draw out the participants' experiences and views as well as their perspectives on care of patients at the end of life and to develop their views on the ethical issues involved and the relevant laws.

### ■ Topic Guide

1. The meaning of the term 'end of life'; what is 'death', definitions of 'death'
2. The types of treatment decisions and decisions in general that are made right at the end of life when the patient is going to die soon, the relevance of religious, cultural, value and belief systems
3. The main ethical issues that medical practitioners face regarding caring for patients at the end of life—what is a dignified death, what is quality of life and value of life?
4. The role of the family in decision-making—elicit whether doctors are aware of lack of legal standing for family consent
5. Whether greater legal clarity in advance directives and advance care planning would help
6. Views on definitions and moral status of withholding or withdrawing treatment, euthanasia or physician-assisted suicide
7. How the Singapore context like the Singaporean medical system, Singapore culture, Singaporeans' beliefs and values, affects all the above things
8. Religious beliefs and their relevance to decisions right at the end of life
9. Views about whether we should change the law to allow physician-assisted suicide or euthanasia—the limits of the role of doctors





## ■ The Analysis and Validation

The interviews were all audio-taped and transcribed from audio to text format. The transcripts were checked and analysed using thematic coding into themes that were identified from the data transcripts. This thematic analysis was carried out using a coding frame which was developed using iterative checking against successive transcripts until a stable version was achieved. Coding was then done using the qualitative software package NVivo 9© to assist in managing the large amounts of information involved. Reliability was also checked using multiple coders for successive transcripts until agreement was reached on the coding.

The results of the thematic analysis were presented at a Validation Workshop with doctors as participants. In this workshop, the doctors helped the researchers to refine their results, check that they have covered the important themes, and that no major issues had been missed out. Furthermore, the Validation Workshop enabled us to check that the analysis and lay report resonates with the doctors, captures their voices and views, and is addressing issues that the doctors considered important for

society to discuss. This report is the product of the analysis after the Validation Workshop. We anticipate that there will be further academic publications of the more detailed results of the research.

Further ethical and legal analysis of the qualitative results will be carried out by the research team.

For further reading on empirical ethics and qualitative methodology in medicine, you can try:

1. Qualitative Research in Health Care (Eds) Catherine Pope and Nicholas Mays. 3rd Edition (12 July 2006) Wiley-Blackwell, London. Paperback: 168 pages
2. Empirical Ethics in Psychiatry (International Perspectives in Philosophy & Psychiatry) (Eds) Guy Widdershoven, John McMillan, Tony Hope and Lieke van der Scheer (14 Feb 2008) Oxford University Press, Oxford. Paperback: 264 pages.

This research was approved by the National University of Singapore Institutional Review Board: NUS-IRB Reference Number: 10-385; Approval number: NUS-1150.

## 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. Recently in 2011, the Foundation released a study of what 30 leaders thought could be done to improve care for the dying in Singapore.





his groundbreaking study addresses an issue of growing importance in Singapore's aging population—medical care for the dying. It does so by providing real data from those actually delivering care to the dying, through interviews with Singaporean doctors practicing in a wide variety of situations. They discuss 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. There is also a section on the law in Singapore in regard to the dying. Medical practitioners, policymakers, families caring for the chronically ill—all would benefit from reading and pondering this report.

A copy of this report may be downloaded from the Lien Foundation website at [www.lienfoundation.org](http://www.lienfoundation.org) and [www.centres.sg](http://www.centres.sg).

ISBN 13:978-981-08-9830-4



9 789810 898304