

TRANSCRIPT

STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

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Dr Ranjana Srivastava.

The CHAIR — I welcome Dr Ranjana Srivastava, adjunct associate professor in the faculty of medicine, nursing and health sciences at Monash University, columnist, presenter and book author. Thank you very much for joining us this evening. Before we invite you to speak I would like to caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you say here today, but any comments made outside the hearing are not afforded such privilege.

Today's evidence is being recorded. You will be provided with a proof version of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website. We have allowed an hour for our session tonight. We thank you for joining us for this hour. I invite you to make some opening remarks, and thereafter the committee will have some questions.

Dr SRIVASTAVA — Good evening, and thank you very much for having me. It is an absolute privilege to be here. I know that you have had a number of experts, and I sort of feel overwhelmed being here. I am not sure how much I can add to the conversation, but I will do my best. I should add that I am an oncologist with 15 years experience, 10 of them as a specialist. I am also one of very few medical oncologists in the public hospital system who also practices general medicine, which essentially means looking after patients with non-cancer illnesses.

What I thought I could be most helpful with would be giving you an insight into the lived experience of an oncologist and of patients who die every day under my care. In the last 10 years I do not think there has been a week in my practice where we have not lost a patient from either a terminal illness like cancer or a non-malignant illness, which might be a progressive neurological disease, lung failure, kidney failure, heart failure et cetera. What I thought might best illustrate my experiences is spending the allocated 5 or 10 minutes that I have initially in reading from my book, because I think that this can form the basis for a lot of our conversations in the next hour.

In this book, *Dying for a Chat: The Communication Breakdown Between Doctors and Patients* (Penguin Specials, 2012), I wrote about a patient who I saw several years ago who was a 90-year-old woman whom I have called Mrs Johnson. She did not have cancer, and that is why I have chosen her in particular, because I think when you are dealing with issues like end of life you need to look more broadly than people suffering from malignant disease. Mrs Johnson came in from a nursing home into hospital with pneumonia. She may not necessarily have required an admission to hospital but ended up being admitted due to various other reasons. Essentially her intravenous site became infected; she was getting antibiotics through that. When a site becomes infected there is a fairly significant risk of developing sepsis. This poor lady, who was elderly, vulnerable and frail, developed multi-organ failure. I want to take you to the point where it was fairly clear to her doctors — and there were many of them — that she was very unwell and she was probably going to die.:

Her latest numbers do look bad. Her kidneys are protesting and something will need to be done urgently.

'Mrs Johnson, there has been a serious change in your health'.

'Mrs Johnson, we need to talk about a difficult subject'.

'Mrs Johnson, we will need your help in this'.

These are the things she needs to hear. Instead, I hear myself saying, 'Mrs Johnson, we will need to work on your kidneys a bit'. I hate its deliberate vagueness, hoping that she will ask me some leading questions that will lead us back on track.

'What will you do?' she asks.

'We will try some fluids and I've stopped any pills that might worsen your kidneys. Sometimes, that's all you need to turn things around', I say, omitting to add 'and many times, despite doing these things, your kidneys keep failing, which means we should talk about the eventuality now'. I suspect I must sound reasonable and reassuring enough because her expression doesn't reflect my private alarm.

Later that day, driving home, I wonder how one day my doctors might relate the news of my renal failure to me. Would they own up to at least partial oversight on their part to its cause? Would they explain things on a need-to-know basis or would they have a full discussion with me about the implications of my condition? Would they think of me as a diagnosis or a person? I know what kind of engagement I would want from my doctor, but I doubt that I will receive it. Medical sophistication will be so much more extraordinary that I suspect doctors will gloss over their mistakes even more easily, because technology may afford them a tempting escape. My thoughts end in a resolve to come clean with the patient.

...

Tomorrow, I will pull up a chair, sit down and ask her how she really is. As things stand, she is receiving day-to-day care, but I would like her to appreciate the big picture: I suspect she is spiralling downwards and I fear that her fate will match her husband's, which is what she dreads most of all. Tomorrow, I promise myself, things will be different — this is not the way I want to practise medicine.

That night fatefully, Mrs Johnson has a medical emergency call for slipping into heart failure. The fluids trickling in to rescue her kidneys overwhelm the delicate function of her heart. Her breathing becomes so difficult that she can't speak and she clutches at her chest in panic. I receive a call at midnight from the senior resident.

'She might have had a heart attack. You know her best to decide how far we should go.'

... Ask me that tomorrow, I want to protest, and I will have an informed answer for you.

I find myself saying, 'She is 90 and has a poor prognosis. I think you should make her comfortable but not venture into heroics.' Although I have privately thought this for some time, I feel deeply torn saying it behind the patient's back. Yet, it's the right decision for her, tired and worn down at 90.

'What does she want?' I add.

'She can't talk, but her daughters want everything done.'

'What did you ask them?'

There is a pause on the line. It's the doctor's admission that although clumsy, he used the only way he knows. 'I said, "If your mum's heart stops beating or her lungs fail, do you want us to let her go or do everything?"' Plaintively, he adds, 'And they said they wanted everything done.'

I close my eyes at the thought of the exchange.

When a doctor paints resuscitation as a stark choice like this, the answer from most families is unsurprising. 'I would do the same,' I say, unable to keep the disappointment from my voice.

'They said you were talking about a discharge date ...,' the doctor adds, reminding me that I too am responsible for my share of false optimism.

'So, what are you going to do?'

'I called ICU.'

'She's going to intensive care?' I ask disbelievingly.

'Well, they have a bed.'

'But that will be terrible for her,' I say to no-one in particular.

The intensive care doctor comes on the line.

'She doesn't look good,' she begins, her voice laden with remonstrance.

'No,' I agree. 'She looked sick when I left.'

'We could take her to ICU but I don't like her chances.'

'I don't think she should go to ICU,' I say.

'Well, it's not that easy. We have a patient who isn't saying much and a family who wants everything done. I'm thinking the easiest thing to do is to take her upstairs, stabilise her heart, filter her kidneys and see which way it goes.'

'See which way it goes' seems code for 'either we or the family will figure out that this is useless'. I am desperate to not have my errors with the patient compounded by another series of futile actions.

'Wait, can't you talk to the daughters?'

'I don't think they are in the mood. And, really, these things should be done by the treating team in non-urgent settings.'

... I observe the rapid parting of our ways. I am suggesting, 'Let us think this through.' She is arguing, 'Not tonight. We will use technology to tide her over until you sort it out.'

I try again —

'My sense is that Mrs Johnson wouldn't want this level of intervention.'

'If we let her die tonight, we may have a lawsuit on our hands.' Unfortunately, this clinches her argument.

In intensive care, the daughters are shocked at the sight of their mother, whom they spoke to only 12 hours ago. They had read her out an email from her sons and talked about her grandchildren. She had asked whether anyone from her nursing home had asked after her in the weeks she had been away, and expressed a desire to get out hospital soon. And now here she is, looking moribund, dwarfed by beeping machines, gowned doctors, bright lights and pensive faces. Was this what became of the patient whose doctors employed the words ‘hope’ and ‘optimism’ in meting out her care?

‘We probably need to intubate her to support her breathing but she is too confused to give consent,’ a new intensive care doctor says to the daughters the next morning. ‘What do you want us to do?’

The daughters’ answer —

‘We want you to fix her.’

‘The thing is, there is only a small chance that she could improve with intubation ... and if her kidneys get worse, we will be looking at temporary dialysis. She could be here for a long time.’

The intensive care doctor believes that his measured words signal to the daughters that they should not entertain following this course of action. But to the stricken daughters, his words are proof that there is still a chance of recovery. There are more superior machines here in intensive care, probably even more skilled doctors and nurses too. There is one-on-one care here, surely a recipe for improvement if there were one. The sickest people go to intensive care because it’s the place that fixes them. Maybe this was where their mother should have been from the start.

‘As long as there is a chance of her pulling through this, we want you do everything.’

The doctor feels cornered. He knows what he would recommend but recognises the unpreparedness of the family to enter a discussion about end-of-life care. Expressing his frustration, he says that he will do the only decent thing he can think of. ‘We will intubate her but review the situation in a day or two.’ While everyone is glad for the temporary reprieve, the doctor rues that like everyone else, he too has selected the easy way out. He curses ‘the system’ for creating the mess.

In keeping with everyone’s expectations — except her children’s — Mrs Johnson fares poorly. Without intensive care she would die, most likely of painless renal failure, but within the walls of this modern wonder which houses the most startling inventions of medical science, she lives. A machine does the work of her lungs and another stands in for her kidneys. Other devices appear from time to time, to draw some more blood, to put in a bit more drug, to give some fluid, to take some away. It’s a matter of time before she develops hospital-acquired pneumonia, which is potentially fatal. She hasn’t eaten in days. The family wonders whether it is the lack of nutrition that is impeding her recovery. There are repeated phone calls from her sons, wanting everything done to keep her alive while they tie up their business and rush home. There are no threats or demands, just pleas, coming from good people who have every faith that doctors save lives. It’s their dear mother’s turn now and the doctors will deliver; it’s only a matter of time. This is how Mrs Johnson begins to receive artificial feeding.

It’s a week in intensive care before her four children come together at her bedside, their tear-streaked faces reflecting disbelief. The most senior doctor has told them their mother won’t improve. He has gone further, recommending withdrawal of care. Their minds are reeling.

They plead for time, in which they seek a second opinion, and a third, all the while praying for signs of improvement. Finally, a full 10 days after her mother entered intensive care, she is extubated and anointed. But to add another tragic twist to the tale, she doesn’t die within minutes or hours, as they had been told to expect. Incredibly, she lasts another 24 hours, with flickering life, enough to drive the point home to anyone who is watching that this whole thing is just wrong.

She hasn’t even died when the recriminations begin. The nurses who cared for her ... say her death was inhumane. The doctors are disheartened — some at their inability to turn things around, the more insightful ones at this revolving suite of very old and sick patients entering intensive care, when their only chance of recovery is theoretical. The children are heartbroken, bewildered that though it feels as if the staff always knew, nobody warned them about their mother’s death until it was about to happen. They are tortured by the decisions they made on her behalf ... Of course, they wanted everything done, but why didn’t anyone explain what ‘everything’ really entailed? There was never really a serious hope for her survival, but why didn’t someone spell it out? Why didn’t someone say, ‘I know you are upset but this is not in your mother’s interest’?

The bureaucrats, always ready to weigh in on doctors demonstrating fiscal irresponsibility, brand the death a ‘negative outcome’ and rue the hundreds of thousands of dollars in bills racked up by a little old lady at the end of her life. They draw graphs and build comparisons — telling the doctors yet again how healthcare dollars ought to be spent. And poor Mrs Johnson, the central figure in all of this — she is dead, a passive participant in her own care, although it’s fair to say she would have decried the events of the last month of her life.

Long after she has died, Mrs Johnson’s case keeps turning in my mind, the taste of dissatisfaction and an unfulfilled contract of care rancid in my mouth. Was it my fault? Or was it a collective failure of imagination of finely trained doctors to separate fact from illusion? ... Who should be held accountable for the family’s deep and ongoing distress that will forever colour their experience of ... —

illness? —

Nearly a month spent in the hospital of a healthcare system —

widely —

regarded as the best in the world and this is all one gets? Dissatisfaction, unhappiness, and recriminations. How did it come to this? If the patient is dead, the family is dissatisfied, the doctors are disillusioned and the bureaucrats are disapproving, who is it that modern medicine claims to serve?

I wanted to read you this because I think it highlights some really interesting issues that I come up with as a clinician. Primary amongst them is the deep desire for people to live. Time and time again in the hundreds and thousands of patients that I have seen, the issue of death does not come up as much as the vexed issue of prolonging life, and I think that is an insight that I can explore with you further.

The CHAIR — Thank you, Doctor, for that really thought-provoking presentation. I suppose that story of Mrs Johnson relates very much to some of the evidence we have received, that with the specialisation of the healthcare system — and you have touched on this in your book, I know, and in your other writings — often patients do not have someone who is taking responsibility for their patient’s care in a holistic sense and in a longer term sense. We have heard evidence from emergency care doctors in rural Victoria about how emergency departments are programmed to save people, programmed to keep people alive and help them get better. We have heard how in other settings — whether at an advanced stage or at a different stage — often there is no-one who is taking an overarching perspective of the patient’s health care. I just invite you to expand on what you have said and what you have obviously written about elsewhere in that sort of context.

Dr SRIVASTAVA — Sure. I think fragmentation of care is rife, and I think the more that medicine becomes advanced and there are technologies and drugs and there is always something else you can do for a patient regardless of whether it may be appropriate or not, I think that lends to a very seductive kind of medicine where you can summon any kind of subspecialist and niche specialist you want. As a result, what is increasingly being lost in medicine is someone to assume ownership of a patient, which is ultimately what a patient wants. There is a saying that the patient does not care how much you know until they know how much you care, and I think one of the things that patients find is they get advice from all directions and supposed care from all directions, and it is difficult for them.

That ties in with the fact that health literacy is abysmal all across the world; Australia is no exception. That makes it really difficult to have conversations with patients because many, many people do not understand, and also there is, I think, still a great unwillingness to want to engage in the nitty-gritty of your own health. I see people all the time where I offer to have conversations with them, and they put their hands up and say, ‘But you’re the doctor’.

I think doctors face a dilemma. On the one hand, we are often blamed for not communicating with our patients, not explaining to people exactly what they are undergoing and what is happening. On the other hand, it is clearly evident that we have a culture that is death denying, that does not wish to necessarily engage with bad news, that does not want to hear it. So there is this real tension in day-to-day medical care as to how much to say to a patient without upsetting them, without upsetting the cart. And when you happen to be one of 6 or 7 or 10 doctors looking after a patient, it becomes very easy then to say, ‘Well, perhaps I am going to draw the boundaries of my engagement with the patient to this’ — to looking after their heart failure but not necessarily looking at the big picture, or if I am the oncologist, I might just deal with the cancer but not with their other existential issues. It is very tempting, it is very common, and I think that the level of poor health literacy and engagement on many, many patients’ part makes that all the more likely that it happens, and it is really unfortunate.

The CHAIR — How do we overcome that? How as a community do we overcome that?

Dr SRIVASTAVA — I think there are two things. Firstly, from the medical point of view I think that better communication is absolutely essential to the delivery of health care. You know, there is a quaint term people use these days for a doctor who sits by the bedside and holds someone’s hand — they are called an ‘old-fashioned doctor’. We need to return those old-fashioned doctors to modern medicine. I think communication in medicine and the teaching of communication skills has always been considered an optional extra. You know, first and foremost a doctor needs to be smart and intellectual, and if they are nice, that is a bonus. But for ages we have tolerated that doctors do not need to be able to speak to you in a language that you can understand provided that they are technically sound. Now I think that has been to our detriment as a society. But medical education is very slow to catch up with the needs of modern medicine and of modern patients.

Even today, if you look at a medical curriculum, there is often token interest paid to the teaching of better communication, the teaching of, say, palliative care, and there is still a lot of emphasis on things like anatomy, physiology. And that is understandable too because, after all, a doctor needs to understand medicine to treat patients. But I think it is a source of dismay to many of us that better communication and teaching doctors about humanity and about empathy and compassion is not more of a core in the curriculum. It is kind of considered to be taken that if you enter medicine, of course you must be nice and compassionate because, after all, you enter medicine to make a difference. But I argue in this book that I read from and in many other places that communicating well with patients is a learned skill, much like suturing is and much like surgery is. It is not something that comes naturally to a lot of people, and, you know, it should not.

We are taking 18 and 20-year-olds and asking them to have conversations with a 90-year-old woman with tons of life experience, with a whole lot of frailties and emotional vulnerabilities, with a gaggle of children who all think differently, with a husband who might disagree with the whole lot of them, with 10 doctors in the mix, and we are saying to a young doctor, 'Here, you go and have a chat to them about their advance care directive and how they would like to plan their end of life'. I would say it is an impossible conversation to have. In some ways medical education and training is not making it any easier for us to have these conversations.

On the other hand there is some interesting data that shows that although many people feel that many patients feel that they value honesty in a doctor and they want to be told the truth — and certainly this is my lived experience too — telling the truth does not make you a popular doctor. In fact there is evidence to suggest that oncologists who tell their patient the truth about their diagnosis and about their dire prognosis are often ranked poorly on their communication skills because people do not like hearing the truth.

If you are a young doctor who has been graded poorly by a patient or treated poorly by a patient because you have tried to sit down and tell them the truth, that has a great impact on the rest of your career, and you can imagine why a doctor may then wish to avoid these difficult conversations, thinking, 'Well, what good did that do?'. If we want to be a society where we truly value honest and open discussions, then we have to take the good with the bad. There is a lot of bad news in medicine, and there is a lot of bad news at the end of life. I commonly see that that sort of thing does not go down well with some people, although I would also hasten to add that many families are incredibly grateful that somebody has sat down with them and had a conversation that should have been had ages ago.

Ms SPRINGLE — The passage in your book that you have read out to us was a worst-case scenario or a very bad situation. In your view what would have made that better? How would you suggest that it be done in an ideal sense? What do you think would have made the difference to the outcome for that family?

Dr SRIVASTAVA — Firstly, I would respectfully disagree. I think that shades of Mrs Johnson are found in every ward by every doctor every day. It is not the worst case scenario. I think you could speak to any number of doctors — from emergency physicians to intensive care doctors, to practically anybody who is a clinician in a hospital — and various versions of this kind of thing would go on. It is not malicious. It is not some sort of an act of commission against a patient or vindictiveness. This happens because medical care is fragmented. This happens because everybody looks after their patch of medicine and does it really well, but unfortunately the patient is not a collection of organs and a collection of diagnoses. A patient is a human being, and what is often forgotten is to look at the human being.

Let us go back to Mrs Johnson and what would have made things better. Perhaps recognition in the emergency department that a 90-year-old woman with pneumonia who was not necessarily severe enough to be admitted into hospital could potentially go home to a nursing home. We then get into the whole different issue of infrastructure that allows you to return a 90-year-old to a nursing home on a Friday night. Practically speaking it does not happen, because a nursing home is not set up and will refuse to take many patients back because they are deemed ill or you do not have nursing staff et cetera. Let us go back from there. She ends up in the hospital for reasons that are not entirely appropriate perhaps.

The emergency department is graded on how many hours a patient is going to stay on the trolley. If that is your KPI, you are not going to be having a 1-hour conversation with a patient about their goals of care should they deteriorate from their pneumonia because you have other issues. You have patients waiting to be seen, you are going to be reprimanded if your emergency department is full and you are on bypass the next morning and it will be all over talkback radio, so the patient gets sent upstairs.

Once they get sent upstairs to a medical ward, they may switch between different teams and different teams of doctors and things can happen. As things begin to progress I think the realisation that things are going badly and somebody needs to sit down, take ownership and have this conversation is hard, because the infectious diseases guy is looking after the antibiotics, the geriatrician is looking after the elderly person's problems, the cardiologist has been brought in to look after the heart failure and the kidney doctor comes by and says, 'No, she does not need dialysis yet'. The question is: which of these doctors should assume responsibility for the patient? That is a real issue.

Ms SPRINGLE — I suppose what I am trying to get at is that you have articulated the problem really well. What is the answer?

Dr SRIVASTAVA — Right. I think the answer in this case was that as her primary physician — which was me in that instance, and this book is really a mea culpa as much as anything else — I should have limited the number of physicians that were becoming involved in her care and said, 'Okay. We need to have a conversation about where this is heading, because it is all very well to treat you bit by bit, diagnosis by diagnosis, but what is the big picture here?'. If that conversation had been had at an early stage, I would have painted a fairly grim picture of what would happen if she went into cardiac failure or respiratory failure, and I would have dissuaded her from going to intensive care. Mind you, that probably only works in a fraction of the time, so I could have this conversation with the best intentions and say, 'Your chances of survival are dismal'. All too often, even in cancer, families say, 'But it is not zero'. It is all very well to talk about better end-of-life care planning, but you have to have the consumer who understands the conversation and is willing to be a part of it. One of the greatest reasons why people have unnecessary intervention and they go to intensive care — or not even intensive care; they have unnecessary interventions and tests on the wards — is that it is really difficult to convey to a patient that more is not better, and this happens across the board in all specialties.

Ms PATTEN — Thank you, Doctor. That was a very moving and poignant piece. I suppose we have heard this reiterated that sometimes it is much easier to treat than have the hard conversation. If Mrs Johnson had had some sort of advance care plan — there had been this conversation when Mrs Johnson had entered into the nursing home and if they could have gone through some scenarios — that is certainly something we have been hearing. Is this the scenario that you would advocate strongly for us to be not necessarily making compulsory but certainly really incorporating into aged-care health?

Dr SRIVASTAVA — I think there is a really good case for everybody to be thinking about having an advance care directive — the older the better, yes — but I think that my lived experience of being an oncologist and a physician is that the hardest thing in these situations is finding any evidence that a patient had ever given thought to the fact that they were mortal. I do not blame patients for it, and I have members in my family who are the same. But you go around at midnight calling up families and saying, 'Did you ever have a conversation about what would happen if something catastrophic happened?', and the number of people who say, 'We never thought this would happen to us' is incredible. 'Yes, we have seen X, Y, Z die', but 'How did you react to it? Did you have a conversation about what if this were you?' 'No, we never went there'.

The greatest problem is not that we do not respect patient's wishes. It is that the patient's wishes are simply unknown to us in the vast majority of cases. Really I would say that we desperately look for any evidence that a patient has ever spoken to anyone who is close, a next of kin, about these wishes because we want to respect them. When it is very clear that someone like Mrs Johnson is dying, we would go out of our way to confirm that with the patient, and if she had ever said to anyone, 'I don't want to go like that. Don't take me to intensive care', rightly or wrongly that is almost as powerful as having a signed document. I think it is the fact we are never sure about people's stated intentions. It is not the lack of a document that makes this difficult.

Ms FITZHERBERT — Is part of the answer to look at some sort of process whereby people are encouraged to have those discussions and possibly record some sort of intended path way before they end up consulting you, or is that just pie in the sky stuff?

Dr SRIVASTAVA — No, this is what the medical profession has been proposing for many years. You will hear about this often, that the best time to have a conversation is perhaps when you have survived an illness and you think, 'What happens if this happens again? What we do the next time?' if you have survived. Absolutely, we encourage all patients to think about these things.

Every patient who comes into my room with advanced cancer, I would have a discussion about the fact that they need to get their affairs in order. Modern medicine and modern oncology treatments can certainly prolong life for a number of months, sometimes even a couple of years or more, but it does not do away with the need to think about what would happen. It is sort of an expecting the best but fearing the worst scenario. I think it is just very difficult to engage people on the subject of their mortality, and this is especially difficult when people are well, but it is just as difficult when people are dying, and I see this all the time.

Mr MULINO — Thank you for your evidence. You have raised through that interesting and poignant study, and more broadly, a whole raft of issues, and some of them are easy to identify, like communication, but harder to fix. As you say, even with more training professionally and at university, it is hard to see how somebody in their 20s can cope with families and multiple desires and people with much more life experience, and there are many other issues you have talked about which are systemic. I guess I am just wondering: are there other jurisdictions, either in Australia or overseas, that you think do a materially better job than we do at handling these kinds of situations that we might learn from?

Dr SRIVASTAVA — I think it is interesting when you say whether exposing younger doctors to communication skills makes a difference in their later life. I actually think it does because I think this experience builds up over time, and if you do not equip younger doctors and younger professionals with the tools to carry forward into their later profession, then they never learn.

Do other people do it better? Well, probably not greatly but I would say that the recognition that doctor-patient communication underpins a lot of the challenges we face with end-of-life care is being materially recognised in many other places, and people are actively going out and doing a better job of fixing and addressing these issues, because there is evidence that if people understand their choices more, if they are more health literate and if we can help them understand their health issues, they make better decisions for themselves. They are more compliant with treatment, they have less chances of having aggressive treatment or choosing aggressive treatment, they have less chances of ending up in hospital sometimes, they are more likely to die at home or in a hospice, they are less likely to be admitted to hospital and this raft of issues stems from better doctor-patient communication.

Mr MULINO — Just a very quick follow-up. I could be wrong in saying this, but my sense was that different medical faculties in Australia for some time now have had quite a varied approach in terms of the breadth of their approach. Some have focused much more on what you might call technical narrow skills, and others have for some time now tried to broaden out what a student's experience is. I am just wondering is there any sense as to whether overtime that has generated some evidence that broadening training has led to better outcomes.

Dr SRIVASTAVA — I think it is too early for that. Firstly, these things are admittedly more difficult to study than how many scans you did on your newly installed MRI machine, which you can count. I think equipping people with soft skills, as they are called — it is a little bit more difficult to study how they affect outcomes, and there are studies that suggest that they do not affect outcomes and others studies that suggest they do. But I think intuitively as a patient I would feel that I would really like my doctor to be able to engage with me, talk to me and be kind and humane towards me, rather than just flourish their technical skills and expect that that is all that is required of medicine.

Ms SYMES — Thank you, Doctor. More of a comment probably than a question, but you have talked about the communication with doctors, and you touched on it with the attitude of Mrs Johnson's daughters and their desire to do everything. My experiences are that it is society that is not ready for some of those conversations as opposed to the doctor. For instance, I was speaking to a woman last week, not in a personal capacity, who was putting her mother into a nursing home. She had several illnesses, and the discussion with the aged-care home around the no-resus things — she said that she put that to them and was made to feel quite guilty. They were kind of surprised that she was making that request for her mother, and that was an aged-care facility. My response was, 'Wouldn't most people in their 80s and 90s want a no-resus order if they have significant health issues?'. The response she received was, 'No, not really. It's not that common'. Is it a societal thing that people expect us to go to the ends to see what can be done?

Dr SRIVASTAVA — In my experience medicine is as subject to consumerism as everything else. If you want something, you go to the shops and you get it, and when you are sick, you come to hospital to be fixed. There is great resistance from patients and from families to discuss bad news. As an oncologist — and I have

extensive palliative care experience — I consider difficult conversations part of my job and part of my obligation. I am very willing to have them, and I feel that I have sufficient training to have them. Yet the barrier that I face is not my willingness to have them but the patient's unwillingness and the family's unwillingness.

To counter that, I will say that for every conversation you do not want to have with one oncologist, there is somebody else — in the medical profession, perhaps — who will say, 'That's okay, you don't need to have these conversations', so I think people also get mixed signals. It is not as if all the profession is onboard about when to have a conversation about your goals of care or end-of-life care et cetera. As a consumer you can find a doctor who will agree. It is called collusion — where the patient does not want to talk about something difficult, the doctor does not want to talk about something difficult and they get along just fine. There is quite a bit of that too.

Ms SYMES — Is there any difference in generations? I purely base this on the fact that younger people who have passed from cancer, as opposed to older people — my anecdotal experience is that their deaths have been better and have been more in their own control, as opposed to when age has been a factor in conjunction with their illness. I do not know whether there is a family influence as well.

Dr SRIVASTAVA — I think it is really difficult to draw from that sort of anecdotal experience. I would not say that I walk into a room and I look at a patient's age and I can immediately say what kind of conversation this is going to be. I should also touch on the fact that in all of this we have barely touched the surface of people from different cultures, different ethnicities, people who do not speak English — that is a whole other conversation, because they are really vulnerable or they have different ideas about who should make decisions. Once again I do not mean to generalise, and I think we have to be very careful — that just because someone hails from a different culture, we cannot stereotype them. But there are many people, many patients, whom I would see in a very multicultural setting who would want the relative or the community to make a decision about them and not themselves, and that is acceptable practice. Not only that, it is reassuring to them that that has happened. That turns patient autonomy on its head as well because the patient is saying, 'My autonomy doesn't count for as much as you think, but my eldest son's does', or, 'I want you to listen to what my daughter says' or what the religious leader says.

The CHAIR — Doctor, just on the point of the engagement for the medical profession and clinicians more generally, much of the evidence we have received thus far and heard has talked about the structural barriers to early conversations and better communication. You have talked about, I suppose, the consumer or the patient and the individual doctor and their preparedness to have those conversations or not. What about the structural barriers that go back to the point about your example of the oncologist or the heart specialist or the kidney specialist all buying in and buying out again? How do you overcome those sorts of structural challenges in the modern medical environment?

Dr SRIVASTAVA — Gosh, that is a philosophical question, I think. Apart from the fact that many doctors, and especially general practitioners, have said that the remuneration for having these prolonged and difficult conversations is quite poor, and I am not an expert on that, but remuneration in various jurisdictions has been raised as an issue — that it is not considered important enough to be remunerated well. That is something else.

How do you overcome barriers? I think about this a lot, and I think it comes down to one's personal moral compass at the end of the day. I do not know how you can legislate these conversations. I do not know how you can make a protocol that says to a doctor, 'Stop. Think more carefully. Should there be a dozen doctors involved in this failing, struggling patient, and who needs to take accountability?'. I think it comes from good leadership. It comes from not having your eye on very immediate KPIs, like how many trolleys are waiting in which room and, you know, what the ambulance queue is like. All these things are important, but I think that when we spend so much of our energy measuring health care by those standards we miss serving the patients who need to have these conversations, because a lot of our mind — as a day-to-day clinician in a public hospital the messages that come to me are about efficient care, not necessarily about stopping, thinking, reflective, compassionate care. I think it is assumed that we can do both, but when you are constantly under pressure to get patients in, get patients out, many physicians have said to me that the 'what happens in between' gets missed.

Ms SPRINGLE — When you talk about good leadership, who are you talking about having that leadership role?

Dr SRIVASTAVA — I think leadership comes from various levels, starting at the top from our recognition as a society and as governments and local leadership that this is how we want to frame our society. But, more immediately, it comes from role models within medicine. There is nothing more powerful than having a good role model in medicine, whom you have seen do good things for patients.

In fact I was just reading some literature today, and there is evidence suggesting that the single biggest difference to end-of-life conversation comes from which doctor you see. That is pretty powerful. So once again we come down to the individual doctor, the individual patient, and having perhaps the moral compass but then the learning to go with it. It is all very well to say, ‘I feel really uncomfortable. This patient needs to have a better conversation about their goals of care’, and then you say, ‘But I don’t know how to do it. I have never seen it being done’. I think that sort of leadership needs to come from the hospitals and from role models. Unfortunately, or perhaps to the benefit of medicine, for a long time our role models have been people who do good science; they are not people who practise the art of medicine. I think that needs to change, and we need to celebrate both.

Ms SPRINGLE — I would be keen to hear your thoughts and reflections around advance care directives and advance care planning, and I guess what you see the role is, how it is working now and how it could be done better.

Dr SRIVASTAVA — It is really important. I think people absolutely need to engage with their own mortality — at least until we find a way to make them immortal. I think that advance care planning is well intentioned but has had very poor uptake in most parts of hospitals and communities. Certainly with the patients I see I think the figures look fairly dismal. The figures show somewhere between only 10 and 20 per cent of the community having any kind of advance care plan, so it is really poor, and that needs to change.

It will take a sustained effort on the part of all stakeholders, including people like us. All of us are going to be sick one day, and all of us are going to die. I think it will take a sustained effort to imprint that in people’s minds that this is a really important part of your health care. Dying well is an important part of living well, having lived well.

Ms PATTEN — Thank you. That is a great segue with the notion of dying well. As an oncologist, obviously you are seeing people who are going to die, as we all are. I am thinking about making those decisions of withdrawing from treatment, and I know that many people do say, ‘That is enough. I would rather have a quality of life than chemo for the next three months, six months or whatever’. Do you see a role where people can also say, rather than just removing treatment, they want to be more active in voluntary euthanasia? I appreciate we have great palliative care, but do you think there is a role for a person to say, ‘I have actually had enough. I have had a great life. There is no more that medicine can do for me’. Would you support that patient’s position?

Dr SRIVASTAVA — I wish that I could give you an informed answer from 15 years of experience. But the most informed thing I can tell you is that in all my career there have been no more than two or three people at most, in the thousands and thousands of patients I have seen, who have said, ‘I have had enough. I want to die’. A lot of people have had enough, and it would be perfectly reasonable for many of my patients to say that, but they do not. What everyone wants — in fact most people want — is prolongation of life, often at the cost of great toxicity. As an oncologist I sit there and I think, ‘Is this really worth it?’, but it is not my decision to make. I see people clinging onto life. I see people who, when you show them the data and it says, ‘This drug may prolong your life by weeks’, say, ‘I will take those weeks’. I think life is incredibly precious and sacred to the majority of people I come across. Although it is valuable to have a debate about euthanasia, my lived experience at least — —

You could say that perhaps people just do not bring it up with me, but I do not think that is the whole truth. I would consider myself to be a fairly approachable doctor, a doctor who has experience in dealing with these conversations, and the majority of my conversations every single day are trying to convince people to not have treatment; it is not answering their questions about wanting to die.

Mr MULINO — One point that I noted in your case study, where the discussions were going on between the doctors, and somebody said that there might be a threat of litigation if we do a certain course of action, and that was the clincher I think you said. I was just wondering, do you think the spectre of litigation is getting worse in our healthcare system over your 15 years?

Dr SRIVASTAVA — I think that in a consumer-driven society you certainly hear more anecdotal evidence of people saying to you on a ward round that they will sue you, that they will take you to court, that they have engaged a lawyer. I think it would not be uncommon for many physicians to encounter complaints that they have to answer. The complaint goes to the hospital, the legal team picks it up and you have to justify what you are doing. Although having lived in the United States for a long time and having close connections with the United States, it is nothing like that. Is it a looming danger in my mind every single day? I do not think so, but to say that it never enters my mind would also be not true.

I think that, yes, litigation and the spectre of litigation, as you put it, does play a role, especially when you are recommending things like withdrawal of care, where you are recommending something that could be argued as care that has departed from what other doctors may do — whether it is reasonable or not is another issue. The other thing is you can always find somebody who would take a different approach to yours and that is the thing — there is seldom black-and-white in medicine, it is all grey.

The CHAIR — Doctor, thank you so much for your time this evening and for the copies of your book, which I am sure we will all read with much interest, following the case study of Mrs Johnson that said so much about the system and how it operates. Thank you very much. I declare the hearing closed.

Committee adjourned.