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New health law website vital for doctors, patients making end-of-life decisions

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Doctors are trained to treat and cure. It's the key reason why many say they have given futile treatment to dying patients, a QUT study of 96 Brisbane doctors who make end-of-life treatment decisions has found.

The study, conducted by Professor Lindy Willmott and Professor Ben White from QUT's Australian Centre for Health Law Research and published in the *Journal of Medical Ethics*, is one in a series of studies by the Centre that has informed the new End-of-Life website, launched today (June 15).

"A national approach to end-of-life law is critical," Professor Willmott said.

"Results from this latest study illustrate the sometimes ad hoc nature of decision making and the vast array of factors that can influence patient treatment at the end of life.

"After studying end-of-life law in each state, even in a simplified version, we found much variation in regulation across the country.

"There have been repeated calls for uniform or harmonized law and this website should demonstrate clearly to policy makers how much variation there is."

Professor White said end-of-life law, even within each state, needed to be simplified.

"The process of trying to describe this law in an accessible way has reinforced how complex it all is.

"This area of law is meant to be used by real people – patients, families and health professionals, not legal experts. This new website is designed to help people know, understand and apply the law to ensure everyone has a 'good' death."

For the most recent study, researchers interviewed 96, mostly senior, doctors in three Brisbane public hospitals from the emergency, intensive care, palliative care, oncology, renal medicine, internal medicine, respiratory medicine, surgery, cardiology, and geriatric medicine disciplines.

"Futile treatment at the end of life is, by definition, treatment given that will not benefit the patient," Professor Willmott said.

"Our research investigated why doctors believe treatment they consider futile is sometimes provided to patients close to death.

"Futile treatment can prolong or increase patient suffering, cause health workers ethical distress and waste scarce health resources but it is entrenched in Western healthcare systems.

"The most commonly cited reason for futile treatment was that doctors said they were trained to treat with the aim of providing a cure.

"A number of doctors said the desire to satisfy patients, families and medical professionals themselves that everything possible had been done also drove futile treatment.

"This was echoed in the finding that the second most common reason given by doctors was that patients or families requested more treatment.

"However, doctors who had witnessed 'bad' deaths due to futile treatment or had experienced the death of a family member reported it had made them less likely to persist with treatment that wouldn't result in a good quality of life for the patient."

Professor White said doctors described wanting to help their patients and not give up hope.

"Where they had an emotional attachment to the patient, they found it difficult to decide further treatment was futile," Professor White said.

"They said communication with patients and families was a further factor that drove futile treatment and attributed it to their avoidance of and discomfort at initiating a conversation on dying.

"Doctors said it often took several conversations to negotiate how and when to withdraw futile treatment from dying patients.

"They reported doing everything possible to manage family expectations and that sometimes they continued treatment to give the family time to accept their loved one was dying, and the medical team time to negotiate withdrawal of active measures."

The study found concerns about legal consequences also influenced the decision to administer futile treatment.

"Hospital factors cited included increased specialisation so that one organ or system was focussed on for treatment when the patient had a number of other conditions. This meant a single intervention to address just one of the many conditions may be futile.

"Doctors also said this 'siloed' approach compounded communication issues between teams in different departments and was a barrier to

coordinated care.

"In addition, doctors said it was hard to stop active treatment once it was started – when a patient is admitted to hospital it is like a 'chain reaction' of interventions. These hospital-related factors mean that once a treatment trajectory has been set it takes more effort to stop and redirect it to a palliative approach than to continue."

More information: Lindy Willmott et al. Reasons doctors provide futile treatment at the end of life: a qualitative study, *Journal of Medical Ethics* (2016). DOI: 10.1136/medethics-2016-103370

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