A Dying Mother, her Filial Daughter, and the Good Samaritan

Edith Terry

Throughout much of April 2017, Hong Kong has been gripped by a saga of a life on the brink, a daughter willing to sacrifice her own future to save her mother, and the extraordinary gesture of another young woman when both daughter’s and doctors’ hands were tied by law. For a few days, it seemed as though Hong Kong’s rule of law could serve as a death sentence for the mother, despite best intentions, superb technology, and one of the world’s best liver transplant teams.

The narrative, which was carried across all media in Hong Kong daily for weeks, is heart-wrenching. On April 11, Tang Kwai-sze, a 42-year-old woman, was rushed to Queen Mary Hospital with acute liver failure. Her 17-year-old daughter, Michelle, begged to donate part of her liver despite being younger than the legal age limit of 18, and when she was refused, took her case to the press. The refusal was based on the ordinance regulating human organ transplants, and both the Hong Kong government and Queen Mary Hospital immediately sought legal views on whether discretion might be allowed since the daughter was just three months short of her 18th birthday. The law is clear on the age threshold for live organ transplants, however, and for three days all of Hong Kong was hanging on the outcome.

Can bioethics provide insights into the issues raised by the Tangs’ case, beyond the upwelling of public sympathy for the principal figures in this drama?

As with any contested situation involving real people and real lives, we need to ascertain the facts. They are clear. Medically, Tang Kwai-sze’s condition was dire. Michelle’s desire to donate was an understandable response to her mother’s condition. Legally, the medical team was bound by prescribed limits. There is no provision for waiving the age limit on donation, even in the case of a willing donor of almost legal age.

The medical team also believed the law rests on sound ethical foundations. Hong Kong’s top liver transplant expert, Professor Lo Chung-mau, was adamant that the law should be upheld. “A minor is a minor,” he told the South China Morning Post. “Whether she’s 17 and nine months, we cannot and should not cross the line. A liver donation from a living donor carries significant risks and only an adult should have the ability and the responsibility to think about whether she would accept the risks.” In addition, a child may feel special pressure to risk donation to save the life of a parent, especially in the Chinese cultural context, where the doctrine of filial piety requires children to do everything in their power to ensure the longevity of their parents.

However, the public, for a variety of reasons, felt the outcome of applying the law and conventional ethical standards was unjust. Cries for reform ensued. Civic Party legislator Dennis Kwok even drafted a short-term bill designed to temporarily legalize underage organ donation, and quickly rounded up bipartisan support for it. In the end, legal intervention proved unnecessary, and an emerging debate about the ethics of the law was temporarily shelved. Dr. Ko Wing-man, secretary for Food and Health, said – not for the first time – that the law was due for amendment to allow for more flexibility in assessing a donor’s eligibility.
Internationally there is no hard and fast rule on the minimum age for donor eligibility, and Dr. Ko said that a legal amendment would give the Human Organ Transplant Board authority to assess eligibility based on their physical condition, clinical, and psychological suitability.

But a legal amendment was not going to ready in time to save Tang’s life. That took another member of the community, alerted by the outcry in the media. A “good Samaritan,” in the Christian Bible and tradition, is someone who performs a good deed for a perfect stranger. Momo Cheng Hoi-yan, a 26-year-old clerk, was moved by Tang’s plight and the daughter’s courage. Cheng arranged to donate two-thirds of her own liver to Tang. Surgery with Cheng’s resection on April 13 was followed by a second operation on April 20, after the blockage of a blood vessel caused damage to the transplant. Nevertheless, the live donor transplant gave Tang just enough time to survive until, fortuitously, a whole liver came available, from a brain-dead patient at Kowloon’s Queen Elizabeth Hospital.

Said Cheng as she was discharged from the hospital: “The past week was important. Without my liver to extend Tang’s life, she would not have been able to wait for one from a deceased donor. I think it was worthwhile to use my 0.5 percent mortality rate [as a liver donor] in exchange for Tang’s 90 percent survival rate.”

The story had a happy ending, with Tang coming out of her coma and her doctors cautiously optimistic 10 days after the first operation. The ethical issues have not gone away, however. If a donor had not come forward, there is little doubt that Tang would have died.

Other patients waiting for transplants have had worse fates. In 2015, a 19-year-old, Jamella Lo, died while waiting for a double-lung transplant, despite public outcry and sympathy. This and other cases have led to questioning of Hong Kong’s Human Organ Transplant Ordinance, which lays down the parameters of the Special Administrative Region’s carefully limited opt-in system. This requires potential donors to declare their willingness to contribute organs after their deaths, by joining a Centralized Organ Donation Register that was established in November 2008, or by applying for an organ donor card. The CODR and card system were set up in part to encourage a change in mindset favoring voluntary donations. Yet Hong Kong’s rate of organ donation remains among the world’s lowest, with 2,508 patients waiting for organs at the end of 2016, against 456 donations, including 276 corneas.

A 2016 research brief by Hong Kong’s Legislative Council Secretariat compared Hong Kong’s 5.8 donors per million people unfavorably to high-donation countries including Spain (39.7 donors pmp) and Croatia (39.0 donors pmp). The waiting time for liver transplants averaged 43 months, second only to the waiting time for kidney transplants. One reason for the long waiting time and low rate of donations is that organ donors can be overruled by families after their death. One recent study conducted at Hong Kong’s largest regional hospital, Queen Elizabeth, found that the overall refusal rate of families was 48 percent, compared to 24.3 percent in Spain, 41 percent in the United Kingdom, and 10.5 percent in France and Belgium.

The causes of Hong Kong’s low organ donation rate are complex but not mysterious. Many observers attribute a reluctance to register as potential organ donors based on Confucian
and Taoist (but not Buddhist) precepts to preserve the physical integrity of the body at death. As late as the Han Dynasty (206 BC to 220 AD), the elite were buried in suits made up of jade plaques that were thought to preserve the mortal body. The cultural explanation only goes part-way, however. The authors of the Queen Elizabeth Hospital study found that in addition to family resistance, institutional bottlenecks were a proximate cause, particularly the over-stretched system of human organ coordinators, with just nine coordinators managing human organ allocation over Hong Kong’s network of 40 hospitals. Only 40 percent of referrals came from Intensive Care Units (ICUs) compared to 90 percent on average in other parts of the world. The study authors found that one-third of the potential organ donors in non-ICU wards were lost, in part due to time lapses in confirming brain death. They suggested setting up mobile teams including ICU doctors and nurses, to advise clinicians elsewhere in the hospital systems to provide support for brainstem tests and potential donor support.

Understanding the problem is one thing. Doing something about it is another. The Hong Kong government addressed the issue of the low organ donation rate most recently in April 2016, setting up a Committee on Promotion of Organ Donation. Improving public relations for organ transplants may be helpful, but has had little visible impact on the numbers. The Legco report found problems with the lack of dedicated teams within hospitals to identify donors as well as the disproportionate ratio of hospitals to organ transplant coordinators. The report stopped short of recommending an “opt-out” system similar to the one in Singapore, where every permanent resident is presumed to be willing to donate organs at time of death unless they have petitioned for an exemption. Even a hard opt-out system is not enough on its own to increase live organ donation rates. Singapore’s organ donation rate was only 6.5 donors pmp in 2015, according to the Legco study.

In the Spanish experience cited by the Legco report, donor rates increased as a combination of the move to presumed consent and an emphasis on getting organs at the time of death. The Spanish system is characterized as “soft” opt—out. Family members are consulted and their consent is required even if the donor has not signed an opt-out form stating opposition to the use of his or her organs after death. Spain’s National Transplant Organization, established in 1989, identifies potential donors and provides training for medical professionals, and is credited with an increase in organ donation rates 10 years after the adoption of an opt-out system in 1979.

Turning back to bioethics, the doctors were legally constrained from accepting young Michelle’s goodhearted and desperate plea. But is the system wrong? In the public conversation about Tang Kwai-sze’s case, the focus returned to the low rate of organ donation as well as the under-age limitation. Secretary for Food and Health Dr. Ko Wing-man promised to hold a consultation on allowing people under the age of 18 to serve as living donors, but added that legal change would be possible only if a “significant majority” backed it. This is a reasonable position in an executive-led governance system like Hong Kong’s, but is it ethical? How exactly would the government determine majority opinion? What questions could it ask to elicit a consensus on values that might form the basis for legislative reform?
Bioethics is not about neat solutions to problems but about thinking through ethically challenging situations where personal intuitions and principles are frequently in conflict. At the level of clinical ethics, the concerns that matter are the need to benefit patients, the responsibility not to harm, the need to respect autonomy and its flip side – the requirement not to allow those who cannot properly consent to make grave decisions, including children, the mentally ill, prisoners, and adolescents generally.

The responsibility not to harm is particularly relevant in organ donation, when there is no medical benefit for an underage donor and there is a prospect of harm. A 0.5 percent mortality risk may seem not much on paper, but 15-20 percent of liver donors may have significant impairments to their quality of life, and for a young person, it can represent a significant cost over a longer period of time than for an adult.

At the level of public policy ethics, policy makers are accustomed to looking at health policy in terms of politics and economics, but the Tang case suggests the need for a broader ethical review. Instead of scrambling for solutions each time a particular case comes to light and elicits public sympathy, the next government review should test the Human Organ Transplant Ordinance against ethical principles, including the widely held view that the wishes of a filial daughter to save a parent should have been honored. On the other hand, encouraging exceptionalism – by good Samaritans or by children – should be a red flag. Neither is an acceptable substitute for improved outcomes in increasing organ donation rates and a general ethos supportive of the organ transplantation enterprise.

A lower age limit for live organ donors may not be out of bounds, although a 0.5 percent death rate for liver donors is high. But to merely adjust the age limit is impulse driven public policy, and on that basis ethically suspect.

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Sources:
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