

# No heart for paediatric heart transplantation in Hong Kong

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On 19 July 2019, it was reported that a 20-month-old boy with restrictive cardiomyopathy due to a rare genetic disease and multiorgan failure had undergone successful heart transplant, making him the youngest-ever such patient in Hong Kong.<sup>1</sup> It is inconceivable why the numbers of donated organs have declined in recent years, nor why Hong Kong Chinese parents rarely donate the organs of their brainstem-dead (BSD) children, despite the potential lifesaving benefit to other children.<sup>2-6</sup> In a local survey on the knowledge and attitudes towards BSD among university undergraduates, the respondents' overall knowledge of BSD was unsatisfactory.<sup>2</sup> Only 24% of respondents knew that BSD was the equivalent of legal death in Hong Kong. Among those who agreed that life support treatment could be withdrawn in the event that they themselves were diagnosed as BSD, only 70% and 76% would permit life support to be withdrawn from a family member or a stranger, respectively.<sup>2</sup> The scenario for a child is unknown but likely worse. Adequate explanation and counselling are important to facilitate family members in coping with this important end-of-life issue.<sup>2</sup>

Over a 16-year period, 22 patients (17.3%) of all deaths in a paediatric intensive care unit were diagnosed with BSD.<sup>7</sup> Among them, the authors recall only four cases of organ donation and included Western and Japanese families. The belief that the body of a child must remain integral with no cutting-out of internal organs is a taboo among local Chinese parents and may be a major obstacle to paediatric organ donation. Such cultural beliefs can take years or even decades to change.

Apart from personal and cultural beliefs, decisions by family members on organ donation are affected by multiple factors, including prior exposure to organ donation information, interaction with the medical team, and the person who first mentions the possibility.<sup>8</sup> Acceptance of organ donation is directly related to the end-of-life experience and grief process<sup>9</sup>; thus, an experienced organ donation coordinator should be informed early to provide open and non-directional counselling and support to the family to increase their acceptance. Clear protocols in identification for possible donors and organ donation processes should also be in place.

Regular educational updates should be provided to doctors and nurses, especially intensivists. Under the current Hospital Authority guidelines in Hong Kong, the BSD criteria do not include children aged <2 years. This definition could be re-evaluated to increase the numbers of potential donors; guidelines for diagnosing BSD in children aged <2 years are available internationally, including in the United Kingdom, United States, Canada, and Australia. Some countries have adopted an 'opt-out' system for organ donation, and a cross-country study has shown that presumed consent countries have a 25% to 50% higher cadaveric donation rate.<sup>10</sup>

The above suggestions might increase the supply of the donor hearts only marginally. The major challenge in paediatric heart transplant is the size, as it has to be size-matched, and this makes the availability even more scarce. The way forward should be developing alternative replacements. Bioprinting of a functional artificial heart will be the ultimate breakthrough in heart transplant; however, there are still many challenges to overcome. Autologous induced pluripotent stem cells might offer new possibilities for building immune-compatible hearts for patients, bypassing the complications associated with heart transplant.<sup>11</sup> Other options include developing smaller implantable ventricular assist devices for the paediatric patients, in order for patients awaiting transplant to be treated in an out-patient setting with fewer complications. The Jarvik 2015 15mm (Jarvik Heart, Inc., New York [NY], United States) is the only implantable ventricular assist device designed specifically for paediatric patients, and it is currently undergoing clinical trials.

If more donor hearts can be made available, heart transplants might even become an alternative to the treatment of complex congenital heart disease, especially in defects requiring staged operations with known high morbidity and mortality. Artificial hearts might be an answer, but it will take another 10 to 20 years before this becomes a realistic option. Until then, stories of successful paediatric heart transplant operations can hopefully raise public awareness and increase the parental acceptance in organ donation.

**Author contributions**

All authors contributed to the concept or design, drafting, and critical revision of the manuscript for important intellectual content. All authors had full access to the data, contributed to the article, approved the final version for publication, and take responsibility for its accuracy and integrity.

**Conflicts of interest**

As an editor of the journal, KL Hon was not involved in the peer review process. Other authors have no conflicts of interest to disclose for this manuscript.

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**Answers to CME Programme**

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**I. Patterns of COVID-19 on computed tomography imaging**

A	1. False	2. True	3. False	4. False	5. True
B	1. True	2. False	3. False	4. True	5. True

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**II. Warfarin control in Hong Kong clinical practice: a single-centre observational study**

A	1. False	2. True	3. True	4. False	5. False
B	1. False	2. True	3. True	4. True	5. True