VIEWPOINT

Conjoined Twins: Bioethics, Medicine and the Law

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Conjoined twins are fused twins resulting from incomplete division of a single blastocyst, 13 to16 days post fertilization (1). Complete division of a human zygote within seven days of fertilization yields identical monozygotic twins (1). Fused body components, overlapping visceral components and impaired organogenesis characterize this anomaly (1–5). Classification of conjoined twins is based on, anatomical site of fixation, with the Greek suffix *pagus* (meaning, that which is fixed) being employed to indicate head (*craniopagus*), abdominal (*omphalopagus*) or pelvic (*ischiopagus*) fixation (1, 2).

Conjoined twins are rare, occurring at rates ranging from 1 in 50 000 to 1 in 200 000 births (3). Clinicians managing conjoined twins find themselves at a crossroad where bioethics, medicine and the law converge (6–9). Surgical separation often places one twin at greater risk of death than the other and clinical decisions often conflict with parental wishes. A recent case of conjoined twins managed at the University Hospital of the West Indies (UHWI) presented such a dilemma to clinicians.

Conjoined twins Jane and Luisa weighing 3.9 kg were transferred from a rural hospital, after being delivered by emergency Caesarian section after "failure to progress" during normal vaginal delivery. Mother, a 19-year-old primigravida, received no antenatal ultrasound imaging. The twins, born at term, were joined from the xiphisternum to the pelvis. They had four upper limbs, but only three lower limbs (*tripus*), because one deformed lower limb was a fused appendage. These xipho-omphalo-ischiopagus tripus twins had what appeared to be a cloacal deformity and no anal orifice. Jane the bigger and more active twin had a normal face. Luisa however had left facial hypoplasia, cleft palate, gasping respiration and generalized cyanosis. Jane had a simple atrial septal defect but Luisa had an uncorrectable cardiac defect, including transposition of the great vessels and a thick inter-ventricular septum. The twins shared one liver situated almost entirely in Jane's abdominal cavity.

By physician's assessment, Luisa was dying because of a poor circulatory system. She was being kept alive only because her circulation was augmented by the pump action of Jane's heart. Eventually toxins accumulating in Luisa's circulation would cause Jane's heart to arrest because of mixing of the twins' circulations. Emergency separation surgery was therefore indicated to save Jane, but this surgery would precipitate Luisa's demise.

This was the moral dilemma facing surgeons aware of the Hippocratic maxim, *primum non nocere*: first do no harm (10). Furthermore, Jane's survival was by no means guaranteed because successful separation of xipho-omphalo-ischiopagus twins is a rare surgical feat (3). The most favourable outcome possible from surgery would be a physically disabled survivor (Jane), with only one leg and a permanent colostomy (3). At a Care Conference convened to clarify treatment and obtain surgical consent, indignant family members, affronted by events at the birth hospital where lapses in patient confidentiality led to the twins becoming the object of unwelcomed attraction, declined surgical consent. Mother felt that neither twin would survive surgery. She felt surgery was tantamount to mutilation and a gratuitous infliction of pain and suffering on the twins. She also feared raising a physically handicapped child in her rural community. An attempt to convene a emergency meeting of the Hospital Ethics Committee (HEC) (11) to provide ethical guidance to the medical team failed, because of short notice and the limited time window available to hold such a meeting if its recommendations were to have effect on patient management. Doctors could not proceed with surgery legally without parental consent (12) and the twins demised within 25 minutes of each other, 15 hours after the Care Conference.

Decision making is a complex issue for clinicians managing conjoined twins. The clinical facts of the case, the welfare of each twin and parental autonomy are important considerations. The surgeon's objective is to achieve twin separation, because by so doing, individuals are created, each with the ability to pursue an independent existence. This fits well into western liberal tradition which places great value on individual choice and freedom. In this milieu, the capacity for self rule defines what it means to be a human being (10, 14). The surgeon therefore separates twins not only for medical reasons but as a moral imperative**.**

The presence of two separate brains is the basis for viewing conjoined twins as two individuals because an independent brain is the essence of existence (6, 7). It follows therefore, that each twin should be managed in accordance with the fundamental tenets of ethical care:

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autonomy, beneficence, non-maleficence and justice. The welfare of each twin must therefore be independently pursued, causing harm to neither.

The relative risk of morbidity and mortality to each twin must be communicated to parents with sensitivity and clarity, because they need this type of information to make an informed decision on whether to give consent for separation surgery.

Although the UHWI clinicians chose to respect parental autonomy and abandon the surgical option, this was not the approach taken by paediatric surgeons in Manchester, England, who, when confronted with a similar dilemma, took an opposite path. These surgeons challenged successfully, in the United Kingdom (UK) Court of Appeal, the decision taken by parents of conjoined twins, to deny consent for separation surgery on religious grounds (13). The parents of Jodie and Mary, being devout Catholics based their decision against surgery on the "Sanctity of Life Doctrine", which holds that human life is created in the image of God and is therefore possessed of an intrinsic dignity, which entitles it to protection from unjust attack (13). Each twin therefore had an equal right to life, which essentially was a right not to be killed (13). The parents of Jodie and Mary held their position even though a no surgery decision meant that both twins would certainly die.

By deciding in favour of surgical separation of the twins, the UK judges sought to apply the "welfare principle", placing the children's welfare above parental interest (8). The welfare principle is a well established principle in English Law, it gives a judge the power to overrule a parent's opposition to treatment if it is in the best interest of the child for him to do so (8). By their decision, the judges effectively sanctioned the killing of Mary to save Jodie on the basis that surgeons were coming to the legitimate self defense of Jodie by removing the threat of fatal harm posed by Mary (9, 13). The view has been expressed that only institutions with wide experience in the complex task of twin separation should undertake such procedures (9, 15). Surgeons at Great Ormond Street Hospital, London, suggested this, implying that Jodie and Mary should be managed there rather than in Manchester, where experience was lacking (9, 15). These same concerns were expressed by the mother of Jane and Luisa, when the prospect of twin separation at the UHWI was introduced. The parent's limited finances and the poor clinical state of the twins made transfer of the twins to a world renowned surgical facility a non-viable option.

Surgeons facing the ethical dilemma of having to sacrifice the life of one child to save another should seek guidance from an authoritative ethical body such as a HEC (11). A HEC is a multidisciplinary group comprised of a physician, a lawyer, an ethicist, a hospital administrator, a member of the clergy and a member of the community. The function of this group is to manage ethical dilemmas that are an inescapable part of hospital medical practice. The HEC should be able to meet at short notice and their counsel should be available to hospital staff and patients' families alike (11).

By yielding to parental autonomy in the case of Jane and Luisa, UHWI physicians respected the normal responsibility of a mother, who being neither incompetent nor negligent, provided no justification for a challenge to her authority.

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