Child donors' psychological risk unknown

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It is accepted medical practice that child siblings, even as young as six months, can be used as bone marrow or blood stem cell donors to save a brother or sister with a life-threatening illness.

- Child donors of blood stem cells and bone marrow to sick

siblings often too young to consent
- Accepted practice to take bone marrow or blood stems to save a sibling
- Not much research on the psychological effects on donor children: new law book
- Child donors need separate clinical team and advocate

Harvesting of marrow or blood stem cells has no therapeutic benefit for the donor child, says Dr. Shin-Ning Then from QUT's School of Law in her new book *Children as Tissue Donors: Regulatory Protection, Medical Ethics and Practice* which explores the ethical issues involved as well as regulations in Australia, the US and UK.

"In Australia, about 32 children donate marrow or stem cells annually and worldwide it is in the thousands," said Dr. Then, a member of QUT's Australian Health Law Research Centre.

"A key ethical problem is that children, who often cannot legally consent, are being asked to submit to a procedure that offers them no physical benefit, and which may carry some physical or psychological risks.

"Physical risks such as those associated with having a general anaesthetic, infection and bone pain, after a large needle is inserted in the iliac crest of the pelvis to draw marrow, are known but there is not much research on the psychological effects on donor children.

"Some small-scale studies have had mixed findings. Being a donor can be beneficial by enhancing family closeness and feelings of pride at helping a brother or sister.

"But there may be a downside for donors such as being left feeling isolated, and abandoned with all focus returning to the sick child, and the

possibility of feeling responsible if the transplant is not successful."

Dr. Then interviewed 14 health care professionals, most of whom were doctors, who had been involved in child donations.

"Doctors acknowledged that they didn't know what the long-term psychological benefits and harms were. Some said they did think twice about it and some would not go back for more tissue from the child donor if they thought the chance of success for the recipient was small."

Dr. Then said the health care professionals recognised that most parents didn't agonise over the decision of one child donating to another – however, a minority of parents did.

"Having one desperately sick child who is in pain and suffering side effects from treatment and another well child can colour their decision-making so that the donor child's fears of physical pain seem relatively insignificant.

"It's an ethically complicated area and the rights and potential outcome for the donor child may be easily glossed over."

Dr. Then said internationally and in Australia moves were being made to have a separate clinical team and an advocate for the donor child.

"The advocate can act as the child's confidante and be prepared to stand up in front of parents and clinicians to champion the donor child's interests," she said.

Dr. Then's research found only Queensland, New South Wales and Victoria had specific legal provisions that provide a mechanism by which a young child could be a donor.

"This usually requires the parents' consent and doctors' assessment of minimal harm to the child, and that the recipient would die or suffer severe harm without a transplant of marrow or stem cells," she said.

"The other states and territories have no such provisions and a court order is required for a child to lawfully act as a donor.

"We need more consistency in the laws regulating child tissue donations. The issue of authorisation of children too young to consent to being a donor needs to be looked at."

Provided by Queensland University of Technology