

# Relatives who decline organ donations face conflict and guilt

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Family members are sometimes unable to carry out their relative's wish to donate organs when they die, because of conflicting feelings between making a gift of life and protecting the body of the deceased, according to research in the latest *Journal of Advanced Nursing*.

Researchers from the University of Southampton, UK, spoke to 26 people who had decided not to let their relatives' bodies be used for organ donations about their views and experiences. The 23 relatives who died ranged from a five-week old baby, who had died of a lung condition, to an 82 year-old man, who died following a stroke.

"Family members who spoke to us were recruited using advertisements in 12 local newspapers, four national newspapers and four hospital intensive care units," explains lead researcher Dr Magi Sque from the School of Nursing and Midwifery at the University.

"Face-to-face interviews were carried out with eight parents, ten spouses or partners, two sons, five daughters and one sister."

An unexpected finding of the study was how many of the study participants and deceased relatives held pro-donation views.

"Despite this, the decision to not donate was still taken," says Dr Sque.

Twelve family members said they were normally positive about organ donation and nine reported that their relative had indicated that they

wanted to be an organ donor. Five said they had mixed feelings about organ donation or knew that their deceased relative didn't want to be a donor.

In six cases, both the relative and the person who died shared the same positive view about donation, yet it still didn't take place.

The most commonly reported reason for declining organ donations was because the family member felt the need to protect the body of the deceased. Fifteen participants told the researchers that they didn't want to relinquish guardianship of the body - they wanted to keep it intact and didn't want it to be interfered with.

Some also expressed concern that if organs were donated, and then found to be unsuitable, the whole process would have been unnecessary. Others felt their relative should be left in peace.

Other factors included:

-- Circumstances at the time of death - people needed time to come to terms with the death of their relative, especially if their death was sudden or their body looked normal.

-- Lack of knowledge - some people said they did not have enough information about what organ donation involved.

-- The donation discussion - issues were raised around the timing and sensitivity of discussions between relatives and healthcare professionals.

-- Witnessing the observable ending of life - some people said they needed to be present when their relative's heartbeat stopped. That could not always happen if their relative was a donor.

“Many family members who talked to us said they felt guilty and selfish about their decision not to donate, particularly if their relative had said they wanted to be a donor,” says Dr Sque. “They were also relieved to discover they were not the only ones who had declined donation.

“One even said that seeing our newspaper advertisement for the study made her feel less guilty because she realised that she wasn’t alone in her decision.

“Most countries that support organ donation have high refusal rates and we hope that this study will provide some insight into why people don’t allow donations to go ahead.”

The researchers conclude that rather than seeing donation as a ‘gift of life’ many relatives see it as a ‘sacrifice’ – that in allowing the donation to take place they are sacrificing their relative’s intact body for an operation that might not benefit anyone.

“Describing donation as a ‘gift of life’ is over-simplistic and does not reflect the depth and complexity of the process,” says Dr Sque.

“Healthcare professionals need to take these perceptions of ‘gift of life’ and ‘sacrifice’ into account when discussing the issue with the families of potential donors. Exploring and understanding their views may help lead to better management of this delicate process and could potentially increase donation rates.”

Source: Blackwell Publishing

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