Holly's Insight

Should Families be blamed for low Donation Rates? – March 2015

Recent press releases by the Parliamentary Secretary for Health Fiona Nash (2015) and the Shadow Minister for Health, Catherine King (2015) have effectively blamed the decline in Australia's 2014 organ donation numbers on the families of deceased people.

Is this the best way to increase Australia's low organ donation rate? There are few Australian who disagree that organ donation provides great human and economic benefit. Many media campaigns over many years have resulted in strong community support for organ donation. Then why do families decline? Remembering, grieving families come from the same community who support organ donation. Of course, there are a small number of people who will not support organ donation and these people are seen in every community, regardless if in Australia or a high donation country like Spain. Like Spain, in Australia their views are respected because we believe in human rights. Therefore, like our politicians, the majority of the population appear to hold the view that it is unfathomable that families decline donation at death, because logic states that when you die you don't need your organs anymore. And like our politicians, people then assume that the decision to decline organ donation is irrational and therefore first person or presumed consent should be legislated.

This is a simplistic and erroneous argument. It is based on 'urban myth' and has the potential to cause significant harm to organ donation and people. The truth is more complex and sits in the availability of standardised processes, transparent organisations and provision of good quality patient and family centred end of life care. Australia needs to improve its donation rate and there is a continuing bipartisan effort to bring Australia to international best practice. Some states in the US have recently introduced 'First person authorisation' and have increased their donation rates by using individual donation Holly's Insight SHOULD FAMILIES BE BLAMED FOR LOW DONATION RATES? 4 registration information from databases to tell families their relative wanted to donate and arranging the donation regardless of the family view (Traino & Siminoff, 2013). In the first instance, it seems to be increasing donation rates, but ethicists and researchers are already flagging the problem that health professionals and the wider community are shocked by the harm to some involved, compounded because people are registering to donate without knowing the organ donation process, with evidence suggesting this leads to a loss of trust and reduction in organ donation (Rady, McGregor & Verheijde, 2013; Verble & Worth, 2012).

In the US, Australia and UK it is known that much needs to be done to improve the care given to patients and families at the end of life, and to improve levels of trust in health care. I argue that good end of life care includes the discussion of organ donation in every death, and quality processes to ensure that the patient and family receive adequate treatment, support and care. Families need to understand and trust the staff involved. However, most hospital staff are still uncertain about organ donation processes which begs the question, how can they give appropriate information and support to dying patients and their families?

Spain remains the world leader in organ donation and continues to improve its performance despite funding reductions. The skill and knowledge required by the health care team is vitally important to increasing organ donation, and this is supported by the head of Spain's organ donation organisation, Dr Rafael Matesanz who recently stated, "We never blame the population, If people donate less, it must be something we have done wrong" (Badcock, 2015).

My research has found most families want to donate and to give hope to others, but importantly, they want to protect their dying loved ones dignity and meaning. If they don't donate, it is generally because the system hasn't helped families when they needed help, information and communication. Patients in intensive care should be allowed to die with dignity, and this requires staff to as far as possible, prevent harm and resolve conflict (Cook & Rocker, 2014). We (society, organisations and health care professionals) abrogate our responsibility when we blame families who refuse to donate. I suggest that rather than changing legislation to change the power dynamic between families and hospitals, we should look to improving our organisational practices and end of life care in hospitals. Families and their dying/ deceased loved ones also have human rights, and they include the right to a peaceful death and organ donation.

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