

There are many complex reasons for South Africa's organ donor shortage

By <u>Harriet Etheredge</u> 9 Jan 2019

At any given time, there are around 4,300 people waiting for organ donations in South Africa. These patients usually need new livers, kidneys, lungs or hearts. But organ donors are in very short supply.



Many countries around the world can't meet the demand for donor organs. Shutterstock

This isn't unique to South Africa. Many countries around the world are unable to meet the demand for donor organs. There are a few exceptions, though. One example is <u>Norway</u>, where a surplus of deceased donor livers has been reported.

So what explains South Africa's organ donor shortage?

Religious and cultural beliefs play a role, because they influence the decisions people make about the remains of their loved ones. Sometimes families prefer that a relative's body remain whole and intact; in other cases it's considered important to bury a person within a certain time frame. But attributing the shortages to these factors alone grossly oversimplifies the issue, as <u>research</u> has shown.

There are many complex elements that keep donor numbers low. These permeate the social fabric from a population and legislation level down to the practice of health care workers in hospitals.

It's important to tackle each of these elements to ease the country's organ donor shortage.

Public perception

At a societal level, religious and socio-cultural practices do play a role in the shortage of donor organs. But in my <u>extensive</u> research into the factors influencing low donor numbers, other issues have come to the fore.

These include a suspicion of the biomedical system in South Africa. Sometimes there are perceptions that doctors and hospitals can't be trusted, or that some aspects of practice are unethical.

Some of these opinions are justified; the so-called kidneygate saga of 2001 is one example of poor medical ethics. This scandal saw "donors" from poor families in Brazil flown to South Africa and paid a nominal sum for a kidney, which was implanted in most cases into wealthy Israeli recipients. The sale of human organs is illegal in South Africa, as it is in most other parts of the world.

The issue is also influenced by a negative and often sensationalist portrayal of organ donation in the <u>media</u>, and <u>reports</u> of unethical research on the continent.

Suspicion breeds distrust. People question what will happen to their loved ones' organs should they suspect that doctors and hospitals profit from donations. In the face of these questions, many families find it easier to refuse organ donation, especially in light of the mixed messages which are often communicated to the public.

Legislation

South Africa's organ transplant legislation is vague. The <u>National Health Act</u> admirably addresses the serious issue of organ trafficking and perverse incentives. It also specifically stipulates that consent to deceased organ donation can be written or oral, and can be given by a mentally competent person in the presence of two witnesses prior to that person's death.

Technically, this means that a next-of-kin consent to organ donation isn't actually required where the person stated a preference to donate during his or her lifetime. But the Act doesn't go any further in adequately addressing the procurement of donor organs from people who are deceased. For example, the law doesn't make it mandatory to offer all eligible families the option of donating a relative's organs after brain-stem death, and the conflicts with common law norms are not resolved.

This has left a vacuum. Questions about the legal rights of a person to decide what is done with their remains after they have died need to be weighed against the family's decision making rights. Families have some common law rights to determine the fate of the remains of their next-of-kin.

As a result, written family consent for organ donation is required in South Africa, though it is not a legal necessity.

Donors are lost at this point. A number of people who would willingly donate may fail to inform their families of their decision. People think that signing up as a donor is enough to guarantee that their organs will be considered for donation upon their death. But telling one's family is in fact the most important thing. Even if a person has signed up as an organ donor during their lifetime, the family can still reverse this decision under the current system. They may be more likely to do so if the decision has not been communicated in advance.

Another challenge is that healthcare workers sometimes face difficult situations, for example, around concepts like brainstem death. This is an essential step in the organ donation process, because only people who are legally certified as deceased can be deceased organ donors. In South Africa, brain-stem death is a legally accepted definition of death. This can be difficult to understand, especially when the patient is maintained on a mechanical ventilator, still looks pink and feels warm. When such a patient has been declared brain-stem dead they are unequivocally deceased. But it can be hard to believe. In our <u>research</u>, we found that this was especially true for nursing staff, for whom the saving and maintenance of life is an imperative goal. There was a sense that the person was being "killed" even though the donor is already dead.

Finding solutions

It's clear, then, that no single factor is keeping organ donor numbers low in South Africa. Policymakers, health care professionals, civil society advocacy groups and academics must work collaboratively to address these issues if the situation is to be improved.

There are a number of countries that have increased their donor numbers by introducing more robust policy. The most notable is <u>Spain</u>, where they have adopted an "opt-out" system under which it's assumed that a person consents to organ donation when they die, unless they have issued a clear, written statement to the contrary.

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