

## End-of-life care and organ donation in South Africa – it's time for national policy to lead the way

South Africa (SA)'s healthcare system has the expertise and facilities to provide solid-organ transplantation for those with end-stage disease. In spite of this, there is a marked lack of legislation and regulatory guidelines from national to hospital level. This has resulted in a sense of uncertainty regarding the roles of healthcare professionals in the end-of-life care of terminal patients and the procurement of organs from deceased donors.

Worldwide, the incidence of end-stage disease for organs such as the heart, liver and kidney continues to rise in excess of the supply of these organs. Similarly, in SA, as thousands wait on national lists, our annual numbers who receive transplants are steadily decreasing.<sup>[1]</sup> The inadequacy of our national transplant service is succinctly reflected in the SA Renal Registry data for 2014.<sup>[2]</sup> While we achieved a chronic dialysis treatment rate of 178 per million population, with most of the expansion of this service confined to the private sector, our kidney transplant rate was only 4.1 per million population. Practically speaking, this translates into many who will therefore receive prolonged interim therapy while awaiting transplant, at huge cost to the healthcare system. In the state sector, where strict rationing has resulted in limited growth, transplantation is the only mechanism (aside from death) that opens up access to the fixed number of dialysis slots. So, not only do low transplant rates compromise those who wait, they also prevent those with newly diagnosed disease from accessing care.

Internationally, there has been a call for the government of each country to assume responsibility for the organ donation and transplantation needs of its society. This should be achieved by accessing its own population resources within an ethical framework that protects human rights. This is termed 'national self-sufficiency'.<sup>[3]</sup> In SA, we have failed, and continue to fail to achieve this goal.<sup>[4]</sup> The question to ask is, why?

Some may think South Africans don't want to donate organs, or that healthcare professionals don't support organ donation, but there is substantial evidence to the contrary. Rather, all of us would like more information that is culturally appropriate to help us make decisions.<sup>[5-9]</sup> In this issue, the article by Crymble *et al.*<sup>[10]</sup> explores potential reasons for low donation rates by focusing on the critical role of nurses in organ donation. This is based upon international work that has successfully addressed low organ donation rates in other countries.<sup>[11]</sup> This study confirms, yet again, that our nurses support end-of-life care and organ donation, but their knowledge base is lacking. We know this. What is new from this research, in the SA context, is how nurses are unsure of their roles in the referral process for end-of-life care and organ donation. So, despite the majority support for organ donation, far fewer nurses participate in this process because they are unclear of their scope of practice. This is particularly relevant in the relatively new field of biomedicine, in which organ donation and transplantation have challenged our definitions of fundamental concepts, such as death. What's perhaps most encouraging is that the overwhelming majority of nurses would follow nationally endorsed clinical practice guidelines that clarified their roles. If this were to be appropriately addressed, it would hopefully result in a more active participation in the end-of-life and organ donor referral process, thereby potentially increasing deceased-donor numbers. These findings pave the way for future research, and provide at least some potential options for consideration to address our persistently low deceased organ donor rates.

In the article by Etheredge *et al.*,<sup>[12]</sup> which explores communication between health professionals who are involved in transplantation, we can see the ways in which this lack of policy may manifest itself in a particularly hierarchical and stressful work environment. The article confirms the central role of nurses and transplant co-ordinators, and therefore supports the argument that clarification of roles in the process would be very helpful.

As a nation, we have a collective obligation to find solutions to our ever-increasing demand for organs. Government's commitment is critical so that we can formulate national policy for widespread public education strategies, simultaneously targeting screening and prevention programmes, while expanding organ donation and transplant services. The research presented here suggests that clinical practice guidelines should be prioritised as a matter of urgency, to clarify the roles of nurses and define their scope of practice in the end-of-life and organ-donor referral process. This could be our first step on the long road to 'national self-sufficiency' for South Africans with organ failure, who wait indefinitely for us to find a solution.

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