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Reflections on Nan's liver transplant

The first liver transplant in Aotearoa New Zealand took place in 1998 following the establishment of the New Zealand Liver Transplant Unit (NZLTU) at Auckland Hospital (Gane et al., 2002). From that time to 30 December 2001, 186 patients were listed for liver transplantation, 13 of whom were Māori (Gane et al., 2002). Furthermore, from 1998 to 2014 a total of 595 liver transplants were performed by the NZLTU (Munn et al., 2014). In 1999 my grandmother, Rēpora Marion Brown (1940-2017), required an emergency liver transplant at Auckland Hospital.

According to Coombs and Woods (2017) Aotearoa New Zealand has low organ donation rates compared to other developed countries. In 2015, Māori made up 15.5% percent of the population (Statistics New Zealand, 2015)¹ and with regard to organ donations the rate of donations from Māori is proportionately lower when compared with non-Māori (Grace et al., 2014; Shaw & Webb, 2015).

¹ Māori now make up 17.1% of the population (Statistics New Zealand, 2021).

Māori donate and receive fewer organs per capita than non-Māori (Lewis & Pickering, 2003). More Māori organ donors are needed (Munn et al. 2014) as “[t]he chance of a good tissue match for Maori or Pacific people is low because very few of them become cadaveric donors” (Roake, 2002, p. 2). However, cultural values and spiritual beliefs about the body and its constituents have an effect on organ donation rates for Māori (Shaw, 2010).

It is generally believed that some Māori oppose cadaveric organ donation on cultural grounds (Roake, 2002). Although this view could be “less widespread than is often supposed” (Roake, 2002, p. 3) and is based around ideas of a “monolithic Maori world view that does not necessarily reflect empirical evidence” (Webb & Shaw, 2011, p. 40).

Roake (2002) argues that low cadaveric organ donation consent rates among Māori may result from “unfamiliarity with the concept of brain death and its acceptance, mistrust of medical staff, and issues such as the retention of organs and tissues at autopsies” (Roake, 2002, p. 3). There is also, Roake (2002) continues, a “general lack of public knowledge of the particular transplant needs of Māori” (p. 3).

Religious concerns too can be a deciding factor for families with regard to organ donation (Oliver et al., 2011). Certainly, ideas about the body, death and dying, are understood differently by Māori and non-Māori (Shaw, 2010). With regard to the dead body of a Māori person, Hudson et al. (2008) argue that “All parts of the body should be kept together if possible, and buried as one” (p. 381). While no explicit reason for this is given, it is a Māori cultural norm that has possibly been “shaped by Christianity” (Rangiwai, 2020, p. 16). While Māori tend to maintain the

notion that a body should expire intact, there is also acknowledgement of the need to respond to changing times (Jones, 2017).

Concerningly, Māori and Pasifika are less likely than Pākehā to receive a transplant (Lynskey, 2015), a phenomenon that occurs too among Indigenous and ethnic minorities in other countries such as the US, Canada, and Australia (Garcia et al., 2012). Certainly, the core of health inequity for Māori is rooted in colonisation (Huria, 2021).

Māori are overrepresented concerning liver transplants due to high rates of childhood hepatitis B virus infection unrelated to lifestyle factors (Munn et al., 2014; Wainwright, 2011b). Wainwright’s (2011a) research found that Aotearoa New Zealand liver transplant patients’ perceptions of becoming unwell were linked to a gradual decline in health (with doctors advising more rest and less stress), along with denial of the eventual liver diagnosis. Nan’s illness, on the other hand, was so sudden that there was no time for her to experience any of this. After a short period of time in Rotorua Hospital and diagnosed with liver failure, Nan was flown to Auckland Hospital with the hope of receiving a liver transplant. Following consultation with the whānau, Nan received a liver transplant after two nights in hospital. Indeed, a whānau approach to discussing organ transplant is preferred by Māori (Jones, 2017). What followed was two weeks of hospital care and many months of out-patient care, accommodated on-site at the hospital at Te Whare Āwhina—a “home away from home” for whānau caring for loved ones at the hospital which has been in place for nearly 30 years (Auckland District Health Board, 2021, n.p.).

Aside from the physical requirements for a successful organ transplant, there is a need for adequate psychological preparation too concerning regular check-ups, the side effects of immunosuppressive drugs—including physical changes to the body such as the rounding of the face and excess hair growth, significant diet and lifestyle changes, and depression (Daar & Marshall, 1998). The psychological impacts of a transplant, if not mitigated, could potentially lead to a deficient level of compliance and result in organ rejection (Daar & Marshall, 1998). In the face of some adverse side-effects, Nan was adamant and determined to take care of her health.

Following a liver transplant, patients experience an exceptional improvement in quality of life (Beilby et al., 2003). Wainwright's (2011a, 2011b) research revealed a number of themes that are relevant to Nan's transplant. These were: gratitude—recipients are grateful for the gift of a donor's liver; liver transplantation as a transformative experience—recipients reassess their lives and reprioritise what is important in life; and communicating with donor families—recipients permitted to write an anonymous letter to the family of a donor, the delivery of which was coordinated by the NZLTU. In addition, Wainwright (2011a) also revealed that some donors expressed gratitude for receiving a second chance at life. This was certainly Nan's experience, which she expressed regularly and candidly.

Nan remained extremely grateful for the gift of a liver transplant. She changed her lifestyle and was inordinately meticulous about her medical regime. Nan also reassessed and reprioritised her life with a renewed focus on family, enjoyment of life, and, of

course, maintaining her good health. She was also permitted by the NZLTU to write an anonymous letter to the family of her donor, through which she expressed her tremendous gratitude.

According to Wainwright (2011a), experiencing a liver transplant roused or changed the patients' perceptions of faith and spirituality in the Divine. Nan had always been a woman of faith (Rangiwai, 2019) with religious beliefs based in the teachings of the Ringatū Church (Rangiwai, 2015). However, her belief in God was magnified by the experience of being so close to death.

Nan had a near-death experience (NDE) which included seeing a bright light and hearing a voice instructing her to "go back" and that "it is not your time". The occurrence of NDEs challenges current understandings of consciousness and its connection to brain function (Martial et al., 2020). NDE's around the world share numerous common elements, suggesting that NDE composition is independent of culture (Shushan, 2018). However, there are also aspects of NDE that pertain to culture and religious beliefs (Shushan, 2018). In Nan's case, she believed that she was returned to life by God to continue to care for and support her whānau. In turn, her whānau cared for her. Certainly, family support is critical to liver transplant recovery (Wainwright et al, 2018).

Nan's liver remains in Auckland hospital and she was always quite proud of the fact that her organ was being studied and had the potential to help medical science. Of course, for Māori, and others, organ retention can be a contentious issue (Hudson et al., 2008). More research concerning the spiritual and tikanga Māori aspects of organ donation and transplantation is required. Māori cultural concepts

such as koha-gifting and utu-reciprocity come to mind concerning the need for more Māori organ donations. Following Nan's liver transplant, our whānau became donors. We frequently acknowledge the power of the organ donor's gift to Nan and to our whānau. Nan's liver transplant took place in 1999 and she died in 2017. She was given a further 18 years of life. While it is up to individual whānau to make decisions about organ donation, it could be time for Māori to develop a more widespread tikanga for organ donation.

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