

# What we can't see: the intimate lived experience of rural New Zealand

Victoria Murphy, Emily Gill

There's a man who is probably dead by the time you read this. He was prominent locally in his community and nationally, and continued his professional work until recently. He had a wife, children and loving grandchildren. He was receiving palliative care and expected to have weeks to short months left in his life.

For a medical student, palliative care placements can be deeply upsetting experiences. Being out here day to day, driving through rugged, rural hill country, under the shadow of maunga, you are privileged to be welcomed into patients' homes, and exposed to crucial truths. One is that patients' true circumstances are an enormous and near-infinite room; and you can only ever catch a glimpse of flashes of light through the keyhole. You gain a heartening respect for the boundaries of your lived experience and situations you can never speak for. In parallel, you learn the importance of trying to get closer to that keyhole.

There was an intensity in entering this man's home; more dimensions than the hospital. First, there we were, in the middle of this rural landscape, on his doorstep. He and his wife hugged us and called us 'guardian angels'. They were so warm toward us, though they were obviously both tired, and under unimaginable stress. His wife would sit next to him on the bed where he lay weakly and wipe his forehead. Lying there—breathing shallow, sweating despite the fan, choosing between pain control and consciousness. I fixated on small pieces of his humanity and the psychosocial context in the room—the beachy smell of moisturiser, the knick-knacks and family photos, the washing basket, slippers, orange walls in the corridor. The palliative care nurse discussed his attitudes towards death, dying and what he wanted in his last days.

The second time we saw him, three weeks later, more family were present. His wife and daughter had made permanent, culturally significant lifestyle changes in his honour. He had been moved to a couch. But only intermittently did he open his eyes, before they would slide shut again. This time we were discussing funeral plans. The family told us they would weave a korowai out of flax, and say karakia. Then they would take him up to the marae for tangihanga.<sup>1</sup> We brushed the topic of organ donation; my mind reflexed back to the lab protocols I knew, but now they seemed a million miles removed.<sup>2,3</sup>

I suppose there are two important aspects to lived experience—knowing yours, and respecting others'.<sup>4,5</sup> Lived experience relies on the idea that there is 'unique personal knowledge about the world gained through direct, first-hand involvement in everyday events, rather than through representations constructed by other people'.<sup>6</sup> I've discovered this to be surprisingly controversial, having had more than a few conversations with people about it. As a future doctor, on my palliative care visits I had my own lived experience and learned what you can't learn from a book. In the first years of medical school, textbooks give you bulleted lists about health inequity—smoking, diabetes, socioeconomic status, housing, mental illness. But there is some limit to how much of the picture you can glean from textbooks, or even the anatomy lab. Trying to piece together a life from the nail polish on a hand. You can learn still more by listening deeply to the patient in their own domain.<sup>7</sup>

What people don't like about the concept of the lived experience is that it means those people affected by a social determinant of health always know the most about it.<sup>8</sup> They

should be leaders in solving the issue. This especially applies to Māori health, where Māori should be in leadership positions at every level of equity measures and decision-making. However, people often confuse 'stepping back' in favour of those with lived experience as a slight to their own ability to experience empathy. In a recent *Spinoff* documentary discussing the resilience found in high-priority rural communities, I heard

this: "Some people glide through life, never really touching the sharp edges that come with highs and lows."<sup>9</sup> The balance between empathy—the exploration of experience beyond our own worlds—versus the wisdom that only comes from lived experience, is a dilemma. I say to any future healthcare professional that, being out here, and touching the sharp edges, is the best we can do to understand.

---

**Competing interests:**

Nil.

**Acknowledgements:**

Thank you to the University of Auckland Faculty of Medical and Health Sciences.

**Author information:**

Victoria Murphy: Faculty of Medical and Health Sciences, University of Auckland, Auckland, New Zealand.

Emily Gill: Faculty of Medical and Health Sciences, University of Auckland, Auckland, New Zealand; Department of General Practice and Primary Health Care, University of Auckland.

**Corresponding author:**

Victoria Murphy, Medical Student, University of Auckland Faculty of Medical and Health Sciences. Email: Vmur259@aucklanduni.ac.nz

**URL:**

[www.nzma.org.nz/journal-articles/what-we-cant-see-the-intimate-lived-experience-of-rural-new-zealand](http://www.nzma.org.nz/journal-articles/what-we-cant-see-the-intimate-lived-experience-of-rural-new-zealand)

---

**REFERENCES**

- Edge K, Nikora LW, Rua M. Different coloured tears: Dual cultural identity and tangihanga.
- Lewis G, Pickering N. Maori spiritual beliefs and attitudes towards organ donation. *New Zealand Bioethics Journal*. 2003 Feb 1;4(1):31-5.
- Ellison-Loschmann L, Pearce N. Improving access to health care among New Zealand's Maori population. *American journal of public health*. 2006 Apr;96(4):612-7.
- Reid K, Flowers P, Larkin M. Exploring lived experience. *The psychologist*. 2005 Jan.
- Newtown K, Andrew. What it's like to grow up poor in New Zealand [Internet]. *The Spinoff*. 2021 [cited 28 April 2021]. Available from: <https://thespinoff.co.nz/parenting/08-08-2017/what-its-like-to-grow-up-poor-in-new-zealand/>.
- Lived Experience [Internet]. Oxford Reference. 2021 [cited 22 June 2021]. Available from: <https://www.oxfordreference.com/view/10.1093/oi/authority.20110803100109997>.
- Hipolito-Delgado CP, Cook JM, Avrus EM, Bonham EJ. The lived experience of cultural immersion. *The Journal of Humanistic Counseling*. 2013 Oct;52(2):191-207.
- World Health Organization. Social determinants of health. WHO Regional Office for South-East Asia; 2008.
- Vinnell K, Spinoff, Andrew, McGregor. Life with the hookers of Hawera [Internet]. *The Spinoff*. 2021 [cited 22 June 2021]. Available from: <https://thespinoff.co.nz/society/24-05-2018/life-with-the-hookers-of-hawera/>.