

Homecoming

Rebecca Gandhi

Final year medical student, University of Auckland Waipapa Taumata Rau, New Zealand. Email: rgan841@aucklanduni.ac.nz

'You're not going to get much out of her', I was advised by a nurse as I went to admit our new patient. A quick end-of-the-bed examination: a Māori woman exactly my age, eyelids closed tight in a grimace, head shaved, skin yellow and mottled. Winona. She had been admitted to the hospice for end-of-life care, with an unrelenting melanoma that had metastasised to her liver and bones. She had had enough. She was angry and tired.

Winona was accompanied by her partner, a young Māori man, Jason. 'Winona, I know it's the last thing you want to do right now, but I need to ask you a few questions to see how we can help you'. This was received by several expletives and intermittent reference to the immense pain she was in. Quiet for a few moments, then, 'Sorry, miss. I'm not usually like this. I'm just so sore.' More quiet. The familiar anxiety that accompanies a distressing clinical situation settled in. More quiet. More expletives. More apologies from both Winona and myself. A little bit of help from Jason. Maybe the nursing staff were right. But, despite not getting a lot from her in the initial interaction, it was clear to me and everyone in the room that Winona was dying. What was not so clear was how much time she had left.

I sat quietly with her over the next couple of days. I was never able to push through her pained exterior and, although it was frustrating to not be able to connect in the way that I wanted to, I had an overwhelming amount of empathy for her suffering. Those carefully drawn lines demarcating the boundaries of the doctor-patient relationship seemed to disintegrate as I began to see her as a sister, a daughter, a partner, a friend. I respected her as a young woman who was fighting to maintain autonomy over the body that remained. Who was I to interject? I simply let her be, let her express her frustration, swear in pain, sat beside her and listened. We tried to manage her symptoms as best as possible with massive doses of opiate analgesia,

anxiolytics and antiemetics. Her grimace never disappeared.

A few days into her admission, the hospice clinical director consulted with Winona. He spent a lot less time trying to obtain a clinical history than I did. He focused on Winona's story. We learned that she had been with Jason for eleven years. They met in school. She was from a small town at least five hours away, and many of her whānau still lived there. In sharing this story, the grimace eased a little, though it did not fade completely. The energy in the room changed. Instead of noticing the sadness, I noticed the love in Jason's eyes. I noticed the unwavering support he had offered throughout her illness. The eleven years they had spent together was an old map, sprawled in front of me in the dimly lit hospice room. Then the clinical director asked, 'Where do you want to be right now?'

'Home.'

Up until that point, my time at the hospice had felt like wading through honey: slow, deliberate, often lingering. With one look at her condition, and a single request, things sped up 10-fold. We were going to get her home. All our options were weighed up – even a ten-thousand dollar helicopter transfer (that was quickly excluded). After hours of conversation with a domestic airline, a transfer via airplane was arranged for the following morning, accompanied by a hospice nurse. We were on track.

I arrived at work the next day and there were at least fifteen people outside Winona's room. The air was solemn.

Winona had died at 4:50am – two hours and ten minutes before leaving for her whenua.

I accompanied my supervisor in certifying her death. Today, for the first time, there was no grimace. I couldn't help but note that she finally

looked at peace. Before we left the room, I whispered, 'Rest easy, sister.' She was uplifted later that day to be buried at her urupā.

I think about Winona, months later. I see her in every dying patient I have encountered since. I see her in every unwell young patient, every unwell Māori patient, and in every unwell patient who does not consider this city their home. The first thing I was told about her, 'You won't get much out of her' was completely untrue. I haven't stopped learning from her.

She prompted me to think deeply about the connections our patients have outside of what we see. The Western model of healthcare places strong emphasis on bettering physical health. Even the palliative care model may not always account for the wider beliefs and core values of some communities. I reflected on the heartbreak that I felt when I learned we were not able to get Winona home and realised that this deep connection to the land is not solely experienced by Māori, but by my own culture too. Perhaps this was why it was so difficult for me to process. It led me to delve into the definition of home. Is home where one lives? Where they were born? Where their family is? Or is it something far deeper, more spiritual, is it the concept that all that we are, will return to the land that birthed us?

The answer lies in the very nature of being human – it's different every time. This is particularly evident in our diverse communities. So, the only way to know is to ask. Alongside effective medical management, health professionals need to start opening up conversations in parallel about what the patient hopes to happen after medical care, so that planning can begin appropriately. I cannot help but think that, if we had asked Winona what she wanted on the first day she was admitted, she would have died on her land. However, this doesn't just apply to end-of-life care, but to routine discharge planning on all hospital wards. Since this interaction, I have made a note to ask my patients where they are from and where they call home. In doing this, I have learned far more about my patients and have developed stronger connections that have allowed me to positively contribute to my team's decisions about treatment. I hope that bit by bit, this active work in understanding serves to improve faith in the

healthcare system, particularly from marginalised communities. There is always room for this kind of humanistic approach to medicine. It does not hinder the traditional method, only enhances it while running in parallel. As the world diversifies, so do we. We grow and we adapt with our patients. We learn about tradition and core beliefs from cultures that are not our own. This is how we continue to show compassion in life and in death.

Compassion may hinder judgement at times. In the initial interaction, I was able to see and acknowledge Winona's suffering, but I was not able to see beyond it. Because of our closeness in age, those doctor-patient boundaries had been blurred and I felt myself suffering alongside her. This prevented me from seeing anything outside of managing her symptoms. Ironically, it was a more distant approach from a fresh pair of eyes that was able to address her needs better, to allow her to tell her story on her own terms. In the interaction just before her death, the beautiful moment of storytelling I experienced with Winona, Jason and our clinical director encouraged me to see them as storytellers. These days, I take time with my patients. I let them weave their stories before I ask them what I need to know. As a medical student in my final few months, I know that time is a luxury that will dwindle on the other side of graduation. I want to utilise this luxury to the fullest extent, for both myself and for my patients. It is one of the most valuable things we can offer.

This piece on culture would be incomplete without highlighting the importance of returning to the land in the context of COVID-19. An article published recently on death and dying in New Zealand in the COVID era states:

*'This thing, tangihanga, it's ours. It is for the living. No one can negotiate with Hinenuitepō, but we can weep together at her feet. We can laugh. We can remember. We can and we must. It's how we begin healing, and as much as possible, that process must not be delayed. But a virus has interfered with the flow of this ancient river, so that now, a mother cannot leave quarantine to dress her son, to hold his hand, to make sure he is set for his journey.'*¹

Dying in isolation is a new threat to the cultural practices that have been kept alive for centuries.

As clinicians in this new age, we will need to develop strategies to keep tradition alive, respect the wishes of the dying, while protecting the wider public. This sphere warrants further research combining the approach of cultural liaison with appropriate public health and microbiological understanding.

When a patient dies in hospice care, a butterfly sticker is placed at their door. I never asked why. In a later attempt to make a profound reference, I researched butterfly migration patterns. My intended metaphor kind of fell flat because as it turns out, butterflies in New Zealand don't tend to migrate. But, at the end of the day of Winona's death, I went to the gardens nearby. I sat with the marigolds and cried. As the tears fell, a small white butterfly accompanied me in my thoughts, and I was filled with her energy. I knew she would be on her whenua by now, surrounded by all her whānau, soon to return to papatūānuku.

In my own culture, white is worn at funerals. I thought the butterfly may have been her, but as I am writing this, I realise it was probably a part of me.

A messenger, adorned in my white sari, set to migrate a few hours south. Just this once. To say thank you. And goodbye.

Names and specific details have been changed to protect the identity of people and whānau involved.

Māori translations (maoridictionary.co.nz)

whānau: extended family, family group

whenua: land

urupā: burial ground, cemetery, graveyard

tangihanga: funeral, rites for the dead

Hinenuitepō: spirit, receives the souls of the dead

Papatūānuku: Earth, Earth mother and wife of

Rangi-nui

Reference

1. Hura NA. All things in life are uncertain, except for this. The Spinoff. (cited 2021 August 29), Available from: https://thespinoff.co.nz/atea/29-08-2021/most-things-in-life-are-uncertain-except-for-this/?fbclid=IwAR1GBD3ZwAqHaJpViHtw-FIxPif9pSZhq5hnbRLCgSezJfify_AMDm-3qRw