

Cancer is increasingly survivable—but it shouldn't depend on your ability to 'wrangle' the health system

May 16 2024, by Kevin Dew, Alex Broom, Chris Cunningham, Elizabeth Dennett, Kerry Chamberlain and Richard Egan



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One in three of us will develop cancer at some point in our lives. But

survival rates have improved to the point that two-thirds of those diagnosed live more than five years.

This extraordinary shift over the past few decades introduces new challenges. A large and growing proportion of people diagnosed with cancer are living with it, rather than dying of it.

In our recently published [research](#) we examined the cancer experiences of 81 New Zealanders (23 Māori and 58 non-Māori).

We found survivorship not only entailed managing the disease, but also "wrangling" a complex health system.

Surviving disease or surviving the system

Our research focused on those who had lived longer than expected (four to 32 years since first diagnosis) with a life-limiting or terminal diagnosis of cancer.

Common to many survivors' stories was the effort it took to wrangle the system or find others to advocate on their behalf, even to get a formal diagnosis and treatment.

By wrangling we refer to the practices required to traverse complex and sometimes unwelcoming systems. This is an often unnoticed but very real struggle that comes on top of managing the disease itself.

The common focus of the health care system is on symptoms, side effects of treatment and other biological aspects of cancer. But formal and informal care often falls by the wayside, despite being key to people's everyday experiences.

The inequities of cancer survivorship are well known. [Analyses](#) show

postcodes and socioeconomic status play a strong role in the prevalence of cancer and survival.

Less well known, but illustrated in our research, is that survival is also linked to people's capacity to manage the entire health care system. That includes accessing a diagnosis or treatment, or identifying and accessing alternative treatments.

Survivorship is strongly related to material resources, social connections, and understandings of how the health system works and what is available. For instance, one participant who was contemplating traveling overseas to get surgery not available in New Zealand said, "We don't trust the public system. So thankfully we had [private health insurance](#) [...] But if we went overseas, health insurance only paid out to \$30,000 and I think the surgery was going to be a couple of hundred thousand. I remember Dad saying and crying and just being like, I'll sell my business [...] we'll all put in money. It was really amazing."

Assets of survivorship

In New Zealand, the government agency Pharmac determines which medications are subsidized. Yet many participants were advised by oncologists or others to "find ways" of taking costly, unsubsidized medicines.

This often meant finding tens of thousands of dollars with no guarantees. Some had the means, but for others it meant drawing on family savings, retirement funds or extending mortgages. This disproportionately favors those with access to assets and influences who survives.

But access to economic capital is only one advantage. People also have cultural resources—often described as [cultural capital](#).

In one case, a participant realized a [drug company](#) was likely to apply to have a medicine approved. They asked their private oncologist to lobby on their behalf to obtain the drug through a compassionate access scheme, without having to pay for it.

Others gained community support through fundraising from clubs they belonged to. But some worried about where they would find the money, or did not want to burden their community.

"I had my doctor friend and some others that wanted to do some public fundraising. But at the time I said, "Look, most of the people that will be contributing are people from my community who are poor already, so I'm not going to do that option."

Accessing alternative therapies, almost exclusively self-funded, was another layer of inequity. Some felt forced to negotiate the [black market](#) to access substances such as marijuana to treat their cancer or alleviate the side effects of orthodox cancer treatment.

Cultural capital is not a replacement for access to assets, however. Māori survivorship was greatly assisted by accessing cultural resources, but often limited by lack of material assets.

Persistence pays

The last thing we need when faced with the possibility of cancer is to have to push for formal diagnosis and care. Yet this was a common experience.

One participant was told nothing could be found to explain their [abdominal pain](#)—only to find later they had pancreatic cancer. Another was told their concerns about breathing problems were a result of anxiety related to a prior mental health history, only to learn later their earlier

breast [cancer](#) had spread to their lungs.

Persistence is another layer of wrangling and it often causes distress.

Once a diagnosis was given, for many people the public health system kicked in and delivered appropriate treatment. However, experiences were patchy and variable across New Zealand.

Issues included proximity to hospitals, varying degrees of specialization available, and the requirement of extensive periods away from home and whānau. This reflects an ongoing unevenness and lack of fairness in the current system.

When facing a terminal or life-limiting diagnosis, the capacity to wrangle the system makes a difference. We shouldn't have to wrangle, but facing this reality is an important first step.

We must ensure it doesn't become a continuing form of inequity, whereby people with access to material resources and social and cultural connections can survive longer.

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