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Accessing diagnosis and treatment: The experience of cancer as wrangling with the system

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ABSTRACT

Long term cancer survival is increasingly prevalent, and the consequences are of sociological and clinical interest. In this paper we deploy the concept of wrangling to emphasise the everyday tussle of survivorship and processes of navigating pathways through what can be an unwelcoming environment. From 2020 to 2022 81 interviews were conducted with people, Māori and non-Māori, throughout Aotearoa New Zealand identified as exceptional cancer survivors, living with a diagnosis of cancer from four to 37 years. Categories of wrangling discussed by participants included wrangling with the public drug-buying agency in Aotearoa New Zealand, wrangling between private and public healthcare systems, subaltern wrangling and wrangling across regions. Wrangling could be driven by the person with the cancer diagnosis, undertaken on behalf of that person by others including family and health professionals, and undertaken by the community. We argue that for most people with long-term cancer survival wrangling is a social practice, but the capacity to succeed in that practice is dependent on a range of factors, including levels of economic, cultural, and social capital. The concept of wrangling provides a contrast to an overemphasis in the survivorship literature on cancer as an individual experience; one largely disconnected from the art and practice of managing (often unwieldy and flawed) systems of care.

1. Background

Cancer is a leading cause of death in Aotearoa New Zealand, but longer term cancer survival is also increasingly likely with 66% of New Zealanders diagnosed with cancer surviving for five years or more (Te Aho o Te Kahu - Cancer Control Agency, 2021). This paper is based on interviews with 81 people living in Aotearoa New Zealand who have survived cancer longer than clinically expected. As participants had long periods of living with cancer and dealing with the complexities of healthcare delivery in New Zealand their stories are a rich source for identifying the practices of cancer patients in responding to institutional and structural constraints. This paper focuses on access to diagnosis and treatment.

We deploy the concept of wrangling to provide insight into ways that people with a long-term cancer diagnosis may be required to work at accessing therapeutic resources within the context of resource and institutional constraints. It is necessary to know something of the particulars of health resourcing and delivery in Aotearoa New Zealand to understand the contexts in which people with cancer need to wrangle and what they wrangle with.

Although New Zealand has a well-funded public hospital system where much of cancer care takes place, there is uneven access to services across the country. This in part results from the concentration of many cancer care services in the major urban centres, but also of, at the time of data collection, the fractured system of service delivery. New Zealand had, up to 2022 when the system was changed, 20 District Health Boards (DHBs) funding and providing health services in their districts. DHBs were bulk funded on a population basis and the governing boards were

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mostly elected locally with further members appointed by the Minister of Health. In funding and provision of services DHBs had to navigate setting priorities for their district, complying with strategies set by the state (Barnett et al., 2009). As DHBs varied in geographical size there were differences in access to services across the country, and there are only five tertiary hospitals in New Zealand that are located in the main cities. In relation to cancer, services are provided by six regional cancer services with DHBs mapped to one of the centres. The centres have struggled to provide access to services on a like basis across the six centres. A number of concerns in relation to this were identified in a 2020 review (Te Aho o Te Kahu - Cancer Control Agency, 2021), including inconsistent practices regarding access to some cancer services in spite of national standards existing. Therefore individual DHBs may have available different resources and services from each other if they map to different regions.

The Pharmaceutical Management Agency (PHARMAC), which determines which pharmaceuticals are placed on the Pharmaceutical Schedule and so subsidised by the state, is a pivotal agency for many cancer patients. As a standalone crown entity, PHARMAC's decisions are made at a distance from central government. This position provides resistance to patient and health professional lobbying (Dew & Davis, 2014). PHARMAC operates within a fixed budget determined by the government. It adopts strategies to contain pharmaceutical costs that limits which pharmaceuticals are subsidised by the state. For example, PHARMAC judges clusters of medicines as interchangeable and suppliers then have to compete to have their medicine listed on the Pharmaceutical Schedule, and therefore subsidised. The financial accessibility of pharmaceuticals for cancer treatment is determined by PHARMAC decisions. Another agency, Medsafe, is responsible for regulating therapeutic products, determining what can come on to the market.

Although secondary and tertiary care provided by the public hospitals is fully-funded by government, a private sector operates. Private insurance can gain holders faster access to specialists through the private system and treatment in private hospitals (McLeod et al., 2004). The no-fault Accident Compensation Corporation scheme (ACC) also covers costs of care that can be provided through the public or private system for cases of accident and treatment injury, but not disease unless the disease is deemed to be due to the nature of a person's employment (Dew, 2002).

Public and private hospitals operate within what can be termed statist medicine, referring to the practices of conventional medicine embedded within the state regulatory apparatus. The regulatory apparatus consists of the legal requirements in relation to diagnosis, prescribing, the subsidising of treatment and medical claims-making (Dew & Armstrong, 2021). Beyond statist medicine people can access a range of other health services and products, referred to here as subaltern health practices, including alternative practitioners, supplements and other preparations, and the indigenous Māori traditional healing approach of rongoā, romiromi, and mirimiri, which are not embedded within the state regulatory apparatus. With some exceptions, these services and products are accessed through personal out-of-pocket purchases or through cultural organisations.

1.1. (Re)conceptualising cancer survivorship

There is a burgeoning sociological interest in cancer survivorship emergent from the proliferation of long-term survivors. Many dimensions of survivorship have been considered including the processes involved in the establishment of survivor identities and subjects (Frank & Solbraekke, 2023), cancer survivors' engagement with lifestyle discourses (Bell, 2010), dissonance between cultural ideals of cancer survivorship and lived realities (Lewis et al., 2021), information pathways for medically underserved survivors (Lefkowitz, 2022), the cultural need to mitigate fear and resist denial of death (Hamilton, 2021), and what normal means for cancer survivors (Plage, 2021). This paper focuses on the ways in which access to diagnosis and treatment was negotiated and achieved by long-term cancer survivors.

Commonly survivorship is conceptualised around biophysical pathology, its control, and biomedical intervention. The elaborate, intricate, and ongoing ways of enacting and stretching out survivorship are often side-lined; these practices operate well beyond the clinic. Such practices – which we describe as wrangling – are often fraught, iterative and creative. Moreover, they take place in complex interstitial spaces between person and structure, expertise and chance; and they articulate the limits of what can be done, and the necessity of making do/making something happen.

We are not the first to deploy the notion of wrangling. Liyanagunawardena (2023) uses the concept to make sense of the practices of people in a resource poor country in accessing healthcare services and products, where there are on-going struggles. She uses this to complement or contrast with Mol's metaphor of tinkering, which refers to minor adjustments to ongoing demands in efforts to maintain health. (Mol, 2008). Wrangling gives a greater sense of an unwelcoming or hostile environment that might have to be traversed, and pathways that must be forged, or potential treatment possibilities denied.

Wrangling is an important conceptual response to typical or normative notions of the steady march of disease/recovery progress, deterioration or indeed success. It accommodates 'progress' and forms of 'improvement', but also encapsulates unevenness in the everyday and the inevitability of temporal disorder. It accommodates the nexus of embodied survivorship and the axis of institutional forms and everyday living (with disease). This allows for an articulation of the push-and-shove of 'mundane' survivorship, more impasse and tussle than linear pathway toward healing/recovery or disease progression. This provides a contrast to an overemphasis in the survivorship literature on cancer as individual; one largely disconnected from the art and practice of managing (often unwieldy and flawed) systems of care.

1.2. Capital and wrangling capacities

Practice, as Bourdieu (1990), emphasised, is assembled through the deployment of capital, and rarely if ever is capital evenly distributed. Differential access and proximity to capital then materialises in institutional forms, offerings and willingness. Material resources include having private health insurance and the financial means to cover potentially substantial diagnostic and treatment expenses. Economics infect the affective momentum of the present, framing the justice (or injustice) of the survivorship journey and fostering differential capacities for wrangling, across bodies, families and communities.

In navigating the complexities of healthcare provision, Shim has developed the concept of cultural health capital, defined as "the repertoire of cultural skills, verbal and nonverbal competencies, attitudes and behaviors, and interactional styles, cultivated by patients and clinicians alike, that, when deployed, may result in more optimal health care relationships" (Shim, 2010, p. 1). Here we are using cultural health capital to denote those culturally acquired resources that better enable patients to negotiate the broader health system to access medical interventions.

In the context of Aotearoa New Zealand Indigenous/Māori cultural capital refers to the knowledge, traditions, practices, and values held by Māori communities that contribute to their cultural identity and well-being. Colonisation resulted in the suppression, erasure, and assimilation of Indigenous cultures, leading to loss of traditional knowledge and practices. However, in the post-colonial context, there has been a resurgence of Indigenous cultural capital as communities reclaim, revitalize, and assert their cultural identities. To illustrate, for some Māori survivors financialised relationships are replaced with notions of reciprocity (Durie, 1999). The 'economy' herein is more (w)holistic, collective and relational, and reaches beyond cost to incorporate the collective value of care and survivorship.

2. Research design

Ethical approval for this research was obtained from the Central Health and Disability Ethics Committee (ref 20/CEN/46). Participants were obtained through the Cancer Registry (57), and through networks or responses to media publicity (24). Three requests were made to the cancer registry. The first requested contact details for lung cancer registrations where the extent of disease was distant (i.e., distant metastases) and the registrant had survived for five years or longer. The second was for those with five years or longer survival with cancer of the oesophagus, pancreas, or with sarcoma or liposarcoma where the extent of disease was distant. The final request was for those with five years or longer survival with brain cancer, liver cancer and endometrial cancers, for the latter two where the extent of disease was distant. Letters were sent out to potential research participants and if interest was expressed information sheets and consent forms were provided.

Additional participants were identified through networks and information about the research disseminated through the media (primarily local community newspapers). Initial information about their diagnosis was obtained and our clinical advisor (ED) assessed if the survival seemed exceptional, in which case they were invited to participate in the study. There is no agreed definition on how to measure the exceptional, and our interest was on the trajectory rather than survival per se, but surviving longer than five years in the face of a predicted survival rate of less than 20 percent has been used by researchers (Hök et al., 2009). For some of these cancers the 20 percent survival rate is less than five years.

Eighty-one participants were interviewed from 2020 to 2022 from throughout Aotearoa New Zealand. Three authors (KC, KD and RE) conducted the majority of the interviews with a Māori research fellow conducting interviews with the majority of Māori participants under the supervision of (CC, also Māori) Forty-six were interviewed in person, but in response to COVID restrictions, seven were interviewed via video-links and 28 by phone, with one hearing impaired participant preferring to respond via email. Of the 81 participants, 36 were male and 45 female, 23 were Māori and 58 non-Māori, and ages ranged from 19 to 97 years. Time since first diagnosis ranged from 4 to 32 years. The most common primary diagnoses were related to the brain (28), lung (16), breast (10) and pancreas (7), with a range of other cancers including mesothelioma, melanoma, and bowel.

Participants were asked what led to their diagnosis, what treatment occurred, what part they played in treatment decision making, what if any non-conventional or non-medical approaches they took, who helped in the process, what they would say to someone who was given a cancer diagnosis, and what helped in their trajectory?

Audio-recordings were transcribed and checked by all interviewers. After the transcriptions had been read and themes identified the research team came together to discuss initial avenues of interest. For this paper the first author read through all the transcripts identifying text related to issues of access to diagnosis and treatment. Most participants talked about forms of what we came to call wrangling, a relevant concept that illuminates the social practices involved and makes a novel contribution to understanding the complex processes of access identified, and in particular to gain a better understanding of interactions between structural and institutional constraints and the agency evident in the practices of participants and their carers and supporters.

3. Results

The analysis is organised into five sections, wrangling for a diagnosis, wrangling with PHARMAC, wrangling between the public and private route, subaltern wrangling and wrangling across regions.

3.1. Wrangling for a diagnosis

For some patients wrangling was required to obtain a diagnosis. This could take the form of a process of eliminating more obvious possibilities before getting to a cancer diagnosis. William (all names are pseudonyms) had a persistent cough and his GP first changed his blood pressure medication. then tried an asthma inhaler, but the cough persisted. As he also had chest pains, he eventually obtained a consultation with a cardiologist who took a chest x-ray "that showed stuff everywhere" and lung cancer was diagnosed. Ava had lung cancer that was eventually identified "after about the fourth bout of antibiotics". Leanne saw her GP about five times for what was diagnosed as an ulcer, and it was suggested to her that as her symptoms did not seem ulcer-like to "lay it on" her GP. She was then referred for a scan and diagnosed with colon cancer. Making something happen required suggestions outside of the clinic on how to wrangle. In these examples patients had to persist in accessing a doctor, presenting with ongoing or different symptoms, before a cancer diagnosis was established. In New Zealand, primary care consultations are subsidised by the state with patients paying the difference (which varies across the country), so wrangling for diagnosis is, to varying degrees, resource dependent.

Sometimes wrangling for a diagnosis was undertaken on behalf of the survivor. Noah had been to his GP several times then went in one day "yellow and jaundiced". His GP was away, and he saw a locum who thought he might have gall stones so "we'll just do a routine referral". A nurse practitioner present whom he had seen before with back pain said, "I think we should refer him straight in because I think there might be something more there." The GP did not support this, and the nurse practitioner then said, "can we go outside?". In this interstitial space outside the consultation room the nurse wrangled as "quite a heated discussion in the corridor" occurred. After that the GP relented and referred Noah to hospital where he was diagnosed with pancreatic cancer. The nurse practitioner wrangled on the patient's behalf to hasten access to a diagnosis.

Tūī was diagnosed with polyps on several occasions but was advised that no further investigations were necessary. On re-visiting her GP she encountered a locum who felt the diagnosis was wanting and elevated the patient to urgent attention at hospital, resulting in a malignancy diagnosis. Tūī believed no action would have been taken had the GP not been on leave. For Toutouwai the practice nurse pushed her to see the doctor (again) because the nurse felt the symptoms were unusual and required additional action. Toutouwai was whakama (embarrassed) because the symptoms concerned her reproductive system. However the appointment was repeated and a subsequent cancer diagnosis was made. In both these cases the survivor had felt assured that no action was needed.

Anthony had stomach pain and had to take time off work "which is unusual for me". He saw his GP and had a blood test that came back "100% perfect". The GP provided no follow up but Anthony's partner, a nurse, was not happy. She got him into the public health system for a scan where "a very observant radiologist picked up something". He was then flown to another DHB "to have a video camera put down and that confirmed the diagnosis" of pancreatic cancer. In Anthony's case we can see the importance of his social connection to his nurse partner, and in turn her social and cultural health capital in gaining access to diagnosis. In addition, the contingent factor of an "observant radiologist" played an important role in the wrangling of the diagnosis.

Susan already had a diagnosis of breast cancer that she had been treated for and when she had trouble breathing she saw her GP who:

> told me someone had had a cough for four weeks and offered me an antidepressant. So I went away. I was angry … I eventually went back and I was diagnosed with lung mets.

The antidepressant was likely offered as Susan had a history of anxiety, and it was three months before she got the chest X-ray that showed the metastases, for which she was referred urgently as "at that point he couldn't hear any breath sounds on my right side".

For many diagnosis was a more straightforward matter, with GPs making referrals in response to symptoms they were concerned about,

and with no wrangling involved. Once diagnosis occurred the process of treatment for some was also relatively straightforward, where they stayed within the public health system and followed the advice given. But for others wrangling could occur subsequent to the diagnosis, in obtaining treatments or follow-up monitoring. The role of PHARMAC and the relationship between private and public care were important elements in further wrangling.

3.2. Wrangling with PHARMAC

Access to cancer drugs is a contentious issue in New Zealand, with examples of lobbying from different cancer groups to have PHARMAC subsidise medications (Gabe et al., 2012). Julie had been involved in Metavivor lobbying, including a march on Parliament, to get two drugs subsidised. Metavivors New Zealand is a Facebook Group for patients who have metastatic breast cancer. When the drugs they lobbied for were funded Julie was able to access them, although she was unable to sustain being on them as she felt fatigued from them, and her neutrophil levels became very low. In this instance the wrangling to obtain state subsidisation of medications was undertaken collectively by patients themselves.

For many participants health professionals suggested medications not subsidised by PHARMAC. Patients wrangled for the costs of these unsubsidised drugs in different ways. For some wrangling was impossible as they simply could not afford the medications. Peter is a ten-year survivor with lung cancer. His oncologist "did say that I could be treated but wouldn't be able to afford it" as it was "fifty grand a month". For context, the median weekly income from wages and salaries in New Zealand mid-2022 was $1189. Noah has been on palliative chemotherapy for six years with pancreatic cancer. His oncologist "asked us if there was any options that required our funding, would we do that and we'd said, 'No, we'd rather not know about that sort of thing.'" In this interview Noah talked a lot about not having earnt enough money to leave his partner in comfort after he died.

Others took up the offer to pay for unsubsidised medications where this did not cause difficulty. Michael was able to have medications that were not funded by PHARMAC paid for by ACC. He has survived ten years with mesothelioma, a condition covered by ACC, and was able to access drugs not on the Pharmaceutical Schedule. He had chemotherapy but "was getting sicker … with the chemo." As chemotherapy was not reducing the tumour it was no longer funded and the treatment was stopped.

For Matt his community wrangled for him.

> I had a lot of friends because I was playing rugby … They did a big funding night and, it was ridiculous, they raised $110,000 … that covered all of my treatment … plus I could use it because I couldn't work.

Matt was diagnosed with a brain tumour and his oncologist advised him to go on an unfunded drug "that wasn't cheap … I think it was about five thousand dollars a time, from memory, and I had that for over a period of six months."

The cost of accessing unsubsidised drugs had consequences for others. Susan has breast cancer with lung, bone, and brain metastases. Before the brain metastases she was taking unfunded Ibrance on the advice of her oncologist and "spent a total of 48,000":

> it's been quite hard seeing probably the consequences of that too, like my parents' savings just going up in cancer treatment that effectively was useless.

William accessed lung cancer drugs that were not subsidised and "It was about 6000 a month, we broke into some savings." Ava was prepared to take "out a bit of a mortgage on the house" for lung cancer treatment that would cost "about a thousand a month" but her publicly-funded radiation therapy was working.

For some medications subsidised by PHARMAC could be inaccessible. Gabrielle had stage 3B melanoma (following breast cancer) but funding for immunotherapy only occurred at stage 4.

Patients access to subsidised medications could vary across time. David's experience shows the complexity of funding. He has adenocarcinoma of the lung and went on a trial with Ceritinib, not subsidised by PHARMAC. He was placed under the control arm of the trial using standard chemotherapy. The trial protocols meant enhanced monitoring, and found that the chemotherapy was keeping the "lesions in my body more or less under control" but not the brain lesions. He was then placed on Ceritinib as he was told it seemed to "control" brain lesions well. A later CT scan showed problems with his liver, so the drug was stopped. After a period of observation he was placed back on Ceritinib, but now had to pay $10,900 for two months of the pill as the trial had finished. PHARMAC then approved another drug manufactured by a different company, which he was put on with no out-of-pocket payment.

Brendan, a physician with chronic lymphocytic leukaemia (CLL), had been on chemotherapy which was stopped as his bone marrow was not tolerating it, had been on a drug trial but that had stopped, and had several blood transfusions. Then "Ibrutinib just happened to come along". Ibrutinib "is registered in New Zealand but it's not funded by Pharmac ….it will cost anything from about 80 grand to 130 grand a year". The drug company gave 100 people with CLL in New Zealand "free medication for as long as they wished". Since then he has been in remission but currently "it is not probably working as well". He suggests being a medical professional probably helped in getting some privileges such as getting on a trial and maybe being one of only 100 who got the non-subsidised drug for free.

Participants' stories illustrate the complexity of the funding environment, where state subsidisation can change, extra wrangling may be required if you don't have a specialist pushing your case, and the resources required to access treatments can be substantial. Participants with fewer resources to call upon may take a more passive position as they do not have the wherewithal to wrangle. Complex processes of wrangling also play out in accessing public and private care.

3.3. Wrangling between the public and private route

Some participants explored the option of going private for treatment that was covered in the public system. Taking the private route could be advised by health professionals. Christine, following her diagnosis of breast cancer, was advised by her surgeon in the public system to go private. Christine thinks there were problems in her DHB at that time, with women being sent to Australia for treatment. Prior to diagnosis she had a mammogram done privately after a locum GP expressed concern about her symptoms. The mammogram did not indicate a problem. but the practice manager of the private clinic was concerned so Christine had an ultrasound at extra cost – and breast cancer was diagnosed. Later she incurred costs in efforts to recover from adverse effects of conventional therapy. Following metastases to her bones, Christine had a very strong reaction to radiation therapy that "burnt" her internally. Her recovery from this was prolonged. She had to build up her strength and this included seeing a physiotherapist who got her "walking" – but this was paid for by "ourselves so what do you do if you're the standard person?"

Susan was told by her GP that she had a "likely three-month prognosis" after metastases from her breast cancer were found in her lungs and bones. As it was coming up to Christmas, she was not able to see the oncologist until February or March and "it was quite devastating". To deal with this Susan took an active role and saw an oncologist in the private system.

A number of participants made use of health or medical insurance that in the New Zealand context can provide access to private (not public) healthcare. Olivia was diagnosed with stage 3 cancer 15 years ago. Two years later secondaries were found in her ovaries and then her bones. She used health insurance for operations. Sophia, who had recurring liposarcoma requiring nine surgeries over 21 years, only used

medical insurance to access radiation treatment privately during a COVID lockdown as she was not sure how long it would take to wait in the public system in that circumstance.

Medical insurance and private care could be used by participants when they deemed public care to be inadequate. Gabrielle was too young to be eligible for publicly funded breast screening. As there was a history of breast cancer in her family she went privately. After finding a lump in her breast ten months after her last private mammogram she went for another mammogram and ultrasound, then biopsy, and breast cancer was diagnosed. Kererū went to her GP with a lump in her breast but was told that "it was due to my breast changing with my age". She and her partner were not "happy with that". As she had medical insurance and was "a strong wahine (woman)" she "just went off to the specialist." She was thankful that she did as ultrasound detected breast cancer and she had surgery in two weeks.

For Andrea the public system failed her, but this enabled her to access Accident Compensation. Andrea experienced an eight-year delay in obtaining a diagnosis of malignant melanoma. When a mass was found following breast cancer screening a biopsy found metastasized melanoma "rampant" in the chest and lymph nodes. Slides of the original melanocytic lesion obtained eight years prior were revisited and found to show a malignant melanoma. This pathology mistake was classified as medical misadventure, which meant she was eligible to receive Accident Compensation support.

William has lung cancer for nine years and two years ago had inoperable brain tumours and a terminal prognosis. He is a university associate professor. He has creatively used multiple ways of accessing diagnosis and treatment. He has been able to access MRI scans as "we pay a pretty big chunk of money every month … for medical insurance." Through insurance he was able to pay for "my private oncologist" from another city, whom he consulted when decisions were being made and at times was able to get access to treatments through this route that were not originally offered. William paid for unfunded drugs, and the MRI scan showed that "shrinkage in the tumours had been dramatic". His private oncologist also ordered MRI scans for him. Also

> I started to hammer emails at (private oncologist) saying, "I think what we really need to do is get you to apply to Pfizer for compassionate access to this drug Lorlatinib," … I'd got a sense that the time would be right for them to be going through the approval process with Medsafe for marketing purposes in which case it would be out of reach, it would be 20,000 a month or something, it would be crazy. Get in on the compassionate access scheme while the going's good. Christmas Eve last year I got a message from (private oncologist) saying, "Good news, it's been approved".

In efforts to access desired treatments both patient and health professionals could be involved in wrangling, particularly well represented in William's story where we see combinations of out-of-pocket payments, the use of health insurance, and the use of a private oncologist who in turn wrangled with pharmaceutical companies to gain access to medications. William's wrangling was particularly successful, in part due to his high level of cultural health capital. He was able to undertake his own research and drew on his knowledge of the system.

Possible access to diagnostics and treatment could also be declined. Kea, who said he was told he "was between level three level four" brain cancer ten years ago, "was offered to go private" but he was "not going to pay for anything" and stayed in the public system, which he assessed as being "pretty quick." Tauhou, was diagnosed with pancreatic cancer seven years ago and given up to one year survival, and the cancer spread to his liver and bones. A form of "radiology therapy" was available in Australia at the time but not New Zealand.

> I had my doctor friend, 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'.

Benjamin, diagnosed with terminal brain cancer, took a similar position. He considered "Gamma-ray" therapy in America, but the cost was too high. There was the possibility of an unsubsidised drug "but that was going to be like 200 grand for a year". His friends said they would get the money "but I didn't want to see people spending all their savings on me."

Wrangling might be required to resist treatments. Gabrielle has breast cancer and then melanoma. For the latter she initially agreed to whole groin surgery but then later declined as it was to be done on her "strong leg" (the other has varicose veins and she limps) and stated, "I would rather have cancer than not be able to walk". She "jumped on the internet and for days I was just reading and reading the research" and found research showing that a full dissection of the groin increased the chances of morbidity and does not change outcomes over five years. She took this back to her plastic surgeon who "was very cross" and said, "are you not afraid to die" and she replied "no, I'm a Christian, I'm not afraid to die, I'm afraid of the process". She then saw her women's clinic surgeon who said he agreed with her.

> his words were, it's a reasonable expectation of you to be able to use your legs … he said, you know the odds, you know, the prognosis, you know, everything, if you choose to rather live five years with quality of life, rather than live 30 years … with all the cancer risks that I have …. I already don't have a prognosis of a long life. So, I might as well have quality for what I have. And that's why we made the decisions that we made.

Gabrielle wrangles on her own behalf, through her own research and in obtaining a second opinion, in the face of stiff opposition.

3.4. Subaltern wrangling

For participants who used alternative approaches not suggested by conventional health providers and not under the purview of statist medicine, out-of-pocket payments were the norm. For most, availability was not an issue, although cost might be. Lara was diagnosed with rare carcinoids of the lung eight years ago, and has multiple health problems, including partial vocal cord paralysis resulting from surgery on her lung, which limits her capacity to work, reducing her income. She states, "I'm taking a cocktail of supplements" and "something is working so I'd be crazy to change it really, even though it's more money that I have to spend but I feel it's a necessity for me."

Kererū accessed high levels of vitamin C after his partner "did some research" and after encountering others during chemotherapy sessions who had used Vitamin C and who were "told they had six months left, and that was 20 years ago" but "unfortunately, it costs a bomb". She now does not take vitamin C but would if she could afford it.

Some faced legal barriers to access in addition to the financial cost. This was the case for those using cannabis products. Christine was prescribed CBD by her GP to help with anxiety that was, however, paid for out-of-pocket as it is not subsidised. In contrast Beatrice, who has adenocarcinoma of the lung and was given three months to live, undertook research and used her savings to purchase black-market products to produce what she termed phoenix tears:

> very very strong cannabis oil … from a whole pound, which is five thousand dollars-worth street value, you get 75 mL. But you take one syringe a day up your bum, and that really helped … the next scan my tumour was slightly reduced. And it continued to reduce for about a year … I had enough money for about a year. And then my rain money ran out.

Luna, diagnosed with breast cancer and later liver metastases, took a singular approach to treatment using illegal substances. She believed that "if you're in a bad space, get rid of it" and that her "bad, down times … that's what was killing me". A help for her was to take MDMA where she "managed to find someone" to provide her with a "little stash" and "I was off my head, having a great time. Lots of loud music, lots of dancing".

For Susan accessing suggested medications was made more difficult and fraught due to efforts to suppress access to some unorthodox treatments.:

> I am taking a lot of worm stuff, which people just find quite funny … So there was a dog worming tablet, or more granules. So, I was getting those in from overseas and customs banned them. So, then I … was getting a worm drench from Farmlands and just like, dosing up on that.

As in other sites of settler colonialism (Barraclough, 2018), Māori in Aotearoa New Zealand wrangle with the effects of colonisation. A unique perspective for Māori was the concept that when a whānau (family) member had cancer, the whole whānau "had cancer". This attitude resulted in a more collective response to helping the survivor traverse, not only the medical system, but also life outside the medical system. These collective efforts then served to wrangle the system. Access to this collective cultural approach was not available to all Māori respondents. Some chose wholly individualised pathways, sometimes keeping cancer secretive from whānau.

Kōkako, who is Māori, was diagnosed with glioblastoma grade 4 brain tumour nine years ago. Four years after treatment it returned and she was given two months to live. She used vitamin C and mirimiri, a form of massage that is an indigenous rongoā treatment. Her husband worked "three jobs just to pay for all of this'". Kōkako pointed out that conventional Western medicine for cancer patients can be paid for by the state but rongoā medicine is not. Kōkako went on to say:

> I'm lucky because I have so much support people. Like, our community held a fundraiser for me, the fire brigade put together a fundraiser to pay for … whatever I needed … I've just been blessed and lucky because I had the funds to do it.

Subaltern wrangling called upon cultural health capital but different sources than for conventional approaches, requiring personal research capacities or being able to call upon others who had that capacity or experience of using alternatives, which could be 'trialled' in iterative fashion to decide on what worked for them. Material resources were crucial, but private insurance did not allow access to the subaltern world. An additional obstacle for some was the legal environment around the substances that they wished to access, and the different support for Western medical approaches and Indigenous health approaches.

3.5. *Wrangling across regions*

Accessing desired treatment could mean leaving the country. Lily was diagnosed with a brain tumour and told there was nothing that could be done. At a friend's suggestion she checked out a neurosurgeon in Sydney. After the friend showed the neurosurgeon her "scans and stuff … I got in within a week and … it was about 50,000 we spent". Tokoeka considered seeing the same surgeon in Sydney. Her diagnosed of fibrillary astrocytoma eight years ago was delayed due to a misdiagnosis in the public system so:

> 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 grand and I think the surgery was going to be a couple of hundred … I remember Dad saying and crying and just being like, I'll sell my business, my uncles are ringing , we'll all put in money. It was really amazing.

However, the Australian-based surgeon "was confident" that the New Zealand-based surgeon "had the appropriate skills". Hazel, diagnosed with grade 4 glioblastoma with a 12-month prognosis of survival, chose to use some of her life insurance pay out to attend an alternative clinic in Australia that cost "many thousands of dollars".

With neuroendocrine tumour of the pancreas, Anthony funded himself to go every two years to Melbourne for a GaTate scan. In 2014 this scan picked up another neuroendocrine tumour in the bowel. He had surgery done privately in New Zealand. In 2020 he went from Wellington to Auckland for the same scan that can now be done there – the scan came back with tumour in the liver. He had to pay his own way from Wellington to Auckland, but insurance covered the imaging. This scan has now been followed up by an MRI in the public system and he has been told that surgery would be an option.

Access to certain treatments could be determined by what region you were in. Oliver went from Canterbury to Dunedin to have stereotactic radiotherapy for brain tumours. His partner says: "You were very lucky to be accepted in … they said they won't usually take Canterbury patients down there … apparently, it's an extremely expensive treatment." To see a brain cancer specialist Kōkako had to travel from home "seven days on, seven days off, taking me away from my whānau (extended family), my home, whenua (land) … that was stressful in itself." Toutouwai, with a diagnosis of endometrial cancer with secondaries in ovaries, was referred to a different DHB for treatment, where. she "felt really alone". After surgery she then spent a further six weeks away from home in that DHB to have radiation.

Citizenship status could be important. When Gabrielle was first diagnosed with breast cancer, she had just received New Zealand citizenship. This was a relief to her oncologist as with her newly confirmed status the cancer could be treated "aggressively, it opens up all the options".

Access to diagnosis and treatment varies across regions and countries making it more necessary for some to wrangle than others. To even get a referral could require persistence and effort, and a referral could mean extensive travel and time away from networks.

4. Discussion

Wrangling is a process of actively traversing pathways through what can be an unwelcoming or hostile environment. Not enough emphasis has thus far been placed on the ordinary, everyday tussle of survivorship, emergent at the evolving interstices of bodies, personhood and systems. Wrangling, as vividly articulated in the stories offered here, goes some way to capturing the messiness of life with serious disease, and the elaborate processes of bringing-together, and making-do, all taking place in an unequal and shifting terrain of possibility and intervention. The bricoleur of the cancer scene, wrangling-*as*-practice cuts across seemingly simple divides between agency and constraint, choice and choice-lessness, hope and hopelessness, wilfulness and acceptance. We note, there are contours to wrangling, it ebbs and flows, some deploy it more than others, and it connects to issues of justice, capital and resources. We are not claiming, however, that successful wrangling leads to better outcomes. Those who wrangle well may get access to more resources, but whether accessing those resources is the reason for long-term survivorship or not requires quite a different sort of study to try to untangle the variety of influences on survivorship.

There were participants who did very little wrangling, or who did indeed tinker. They were comfortable following the advice of their conventional health professionals and happy to hand responsibility for decisions to others they deemed to be experts,. Their treatment could be undertaken within the public health system in a timely manner. But for many participants there was, at least at some stage during and since their diagnosis, a situation that was wrangled with, and there is always the prospect of having to wrangle in some way in the future. The more resources that one has, material, social, cultural, the greater the chances are of successfully wrangling.

Wrangling could take many forms including activist groups lobbying to fund drugs, individuals weighing up private options, accessing illegal products, obtaining fund-raising support for treatments and going overseas to obtain treatment. Having the financial wherewithal to access products and services, whether conventional or unconventional, played an important role in the success of wrangling. Communities could be involved in wrangling, as with the Metavivors Facebook group and the

fire brigade and rugby club raising money. Health professionals could be wranglers, obtaining access to pharmaceuticals and trials. Partners and others could wrangle to gain access to services. And there were many obstacles that required wrangling, such as clinical guidelines that provided a route into treatment or prevented it, PHARMAC decisions, legal restrictions on what could be accessed, and what was available regionally.

It has been suggested that cancer patients enact the neoliberal subject in exemplary ways, as productive citizens exercising choice, but such suggestions obscure the cruelty of imposing a normativity of 'choice' in situations of life-limiting illness (Lewis et al., 2021). Our participants could indeed be entangled in neoliberal forms of governmentality – seeking out private insurance, taking on responsibility and so on. But this is far from the dominant subjectivity for our participants. They actively lobbied the state for more resources, seeing the state as responsible for healthcare. Some participants refused engagement when out-of-pocket expenses were involved. Some participants interacted with communal efforts to support them in various ways, but not as an individualised, isolated, and responsibilised subject. On the one hand they could gratefully accept that support, and on the other refuse to have communities and families' resources poured into expensive treatment regimes.

The role that health professionals play in patients' agencies is also notable. In this research we have examples of oncologists informing patients about non-subsidised drugs, lobbying to get patients compassionate access to drugs, wrangling to get a diagnosis, and to get patients on trials. But what we do not know is who they choose to support, or why they chose to support, in these discretionary ways. Are inequities in cancer care outcomes reinforced as health professionals respond to those with high cultural health capital? Are those better resourced patients with private insurance further resourced through the contacts they have in the private sector? This research suggests that such may well be the case. Conversely we see some examples of survivors with low cultural health capital who are supported by health professionals and family members who wrangle on their behalf. Increasing the awareness of the context and importance of wrangling can help inform healthcare professionals about the impact of their decision-making. If future research could track cancer trajectories more in-depth information could be provided to indicate where and when wrangling becomes most important, information that could inform guidelines to support cancer survivors.

An absence from our participants' stories is any frustration or anger directed at the pharmaceutical companies who produce sometimes extraordinarily expensive medications. Pharmaceutical companies have been able to stay out of the wrangle with individual patients, patient support groups, and community groups. Rather, lobby groups, through their activities, could actually support the pharmaceutical companies (see Mulinari et al., 2022) We had no stories of lobbying efforts to get drug companies to lower their prices. In the New Zealand context, the drug company wrangle, if there is one, is primarily by PHARMAC over subsidising often expensive drugs so patients can access them.

We have explored wrangling in relation to accessing diagnostic and treatment services, but this is not the only sphere in which people with long term diagnoses of cancer may wrangle. There have been some instances noted where participants gained access to clinical trials. This is a complex process of wrangling in its own right, so has not been developed in this paper, but for some this route to care has been important. As noted elsewhere, lifestyle change and imperatives to diet and exercise can be prominent for people post-diagnosis (Bell, 2010), requiring other forms of wrangling and tinkering. People may modify what they do, what they consume, and the environment in which they live. Also, there are likely other events and issues that participants wrangled with that did not arise in the interviews.

Wrangling as a concept provides insights that may be missed by utilising other common concepts and metaphors used in cancer care and heath care more generally. For example, a commonly used metaphor is that of navigation (Reblin et al., 2022), which suggests a map of known territory. This concept is undoubtedly useful in situations where service availability is known and the focus is on accessing the best service, but it does not serve so well for participants like ours who often sought out services that were not so evidently available, or serve to understand the complex of interactions between patients, carers, families and communities that can enable or hinder access to resources. The concept of patient advocacy, where groups come together to lobby for access to resources such as research on or treatments for cancer conditions (Lindén, 2021), is evident in our research, such as the Metavivors group. This is an example of a collective enabling wrangling on behalf of those with particular diagnoses. And as a final illustrative example, patient empowerment, through which patients may gain a greater mastery of their situation (Jørgensen et al., 2018), can be faciltated through processes of wrangling.

At another level of analysis there is a well-established relationship between inequalities and cancer outcomes (Broom et al., 2009; Hill et al., 2010). The concept of wrangling provides a means of understanding the relationship between individual or collective resources and outcomes. That is, the kind of resources that one can call upon, which vary by one's structural position, will influence one's capacity to wrangle, or the possibilities of others wrangling on one's behalf.

A cancer diagnosis and its sequelae can be severely disruptive (Trusson et al., 2016). This dramatic event can require adjustments in sense of self and changes in identity. This paper has focused on wrangling in relation to diagnosis and treatment, but equally wrangling could be considered in relation to other aspects of cancer, such as the forging of new identities and responding to suffering.

Mol (2008) suggests that care is an intervention between people and materialities. Broom and Kenny (2021, p. 43) argue that cancer is a social practice, and that a "practice-based frame centres the body as part of a complex system of affective relationships between patients, family members, carers, doctors and institutional regimes of expertise and care"(Broom & Kenny, 2021, p. 43). Wrangling is a feature of the social practice of cancer. We propose that the concept of wrangling, when people are forced to navigate what can be to them a hostile environment, offers insight into the experiences of those given a diagnosis of a life-limiting cancer.

CRediT authorship contribution statement

Kevin Dew: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. **Kerry Chamberlain:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Writing – review & editing. **Richard Egan:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Writing – review & editing. **Alex Broom:** Conceptualization, Formal analysis, Funding acquisition, Methodology, Writing – review & editing. **Elizabeth Dennett:** Conceptualization, Funding acquisition, Writing – review & editing. **Chris Cunningham:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Supervision, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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