


# 6 The Road Less Traveled: Perspective From an Australian Oncologist

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He had been diagnosed with metastatic colorectal cancer in his late 30s and was responding well to first-line treatment. Physically fit, with a good tolerance to therapy, there was no stigma of sickness or telltale signs of cancer lurking around him. His partner usually attends with him, offers polite nods, few questions asked, but you could sense her underlying nervousness and fear of the unknown. Between the short phrases of broken English and the interpreter talking, consultations were usually pleasant, the right questions were asked, and I would end the consultation by asking how his family was doing back in Vietnam.

Born to Chinese-Vietnamese parents in a city on the outskirts of the capital, he migrated to Australia 10 years ago. He worked hard, exercised, ate a healthy blend of an Asian and Western diet, and check-boxed all the requisites to build a good life.

On this occasion, his cancer was slowly progressing although remained largely asymptomatic. His optimism stayed stable, and he kept his full-time job. I discussed switching treatment.

“Do you have any questions?”

As I shuffled the consent form, information sheets in Vietnamese, pathology form, imaging request, and follow-up bookings, I waited for the interpreter on the other end of the phone to speak. COVID-19 was still lingering, and our face-to-face interpreter service had largely been replaced by phone calls.

My now 40-year-old patient, alone today in the clinic room, looked at me and the care coordinator, then spoke something to the phone.

The voice on the other end said he has no questions, he is “keen to get on with it.”

“Ok then, we’ll get him to sign here, and I’ll need your healthcare interpreter number too.”

An exchange of words ensued, perhaps some things were repeated over. Then my patient smiled, and waited.

“He says thank you doctor but he doesn’t want any treatment.”

It was not the answer I was expecting.

I had explained his slow disease progression, multiple lines available, and good tolerability of treatment, maintaining his quality of life and maximizing survival. I had gone through the projected life expectancy at this point, which was still measured in the order of short years if we pursued all standard therapies.

“Can you ask him again? That he does not want any treatment?”

Perhaps the interpreter had not relayed what I said. Perhaps I had not emphasized the benefits of continuing treatment. Perhaps there were misplaced reasons for declining evidence-based treatment, the clues of which I had learned to pick up quickly, gleaned from conversations over family dinners from my own family of migrants.

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When my patients decline treatment in a context where the clinical benefits clearly outweigh potential harm, I often feel I have not done enough. If I spent more time talking them through their decision making, guiding them through hypothetical what-if scenarios, then would we have gotten to the same page? Was I sure they were *compos mentis*? Should I call the other listed relatives and have the same conversation with them?

In his case, he had made a capable and informed decision.

We are used to the well-trodden path of exhausting appropriate standard treatment before transitioning to a best supportive care approach. However, when patients choose the less traveled path where their cancer journey and life expectancy are truncated by choice, we may struggle to understand their decision. I felt a sense of frustration at his polite declining of potential years of life and unfairness when the next patient, unfit and exhausted of all therapies, begged for more treatment options or anything that could give them another extra day.

I sought to try to better understand the reasoning behind his decision. I have encountered many culturally and linguistically diverse (CALD) patients throughout my journey as an oncologist and personal experiences in my own migrant family. Our health district has one of the most diverse populations in the state, with one in 10 having limited English proficiency. Almost half the population speak a language other than English.<sup>1</sup> We often see as many interpreters as patients in the waiting room, multiple extended family members crowding into small consult rooms, and multitude of language translations of patient booklets being the only recognizable information to new patients in an otherwise foreign cancer center. I understood the importance of cultural awareness, and that cultural differences feed into decision making. But what were the beliefs, concepts, and cultural norms that shape what they do and value?

An Australian study investigating the attitudes of Chinese migrant patients toward cancer identified several key areas including the nondisclosure of a poor prognosis, importance of family in mediating between health professionals and patients, incorporation of Chinese culture-specific treatment, importance of interpreters, and psychological and spiritual support.<sup>2</sup> Chinese patients use combat strategies on the basis of traditional Chinese medicine, Chinese beliefs of food to maintain health, exercise with Qigong, Feng Shui/spatial organization, and ancestor worship.<sup>3</sup> Chinese illness conceptualization includes concepts of karma, fate, and retribution.<sup>4</sup> There are recurring themes that arise, with another study highlighting the importance of the Chinese beliefs in fate and luck, ying and yang, stoicism as a coping mechanism, importance of family, fear of losing face, and denial of diagnosis as a means of protecting the family.

A common thread of family playing an essential role, rather than a patient autonomy approach, was evident. There is a

need to incorporate these beliefs into culturally appropriate programs.<sup>5</sup> Sadly, not much is known about the cultural impacts on patient decision making. Research into race, culture, and ethnicity is thought to be too restrictive.<sup>6</sup>

Research investigating interventions to improve patient-centered care and participation in the treatment process in CALD has found positive effects of culturally tailored video and patient navigator interventions.<sup>7</sup> A recent review also found patient navigation as an effective strategy in improving patient care, from screening through to diagnosis, treatment initiation, and likely also in the active treatment and survivorship phase.<sup>8</sup> Importantly, cultural barriers were evident. An Australian study looking at CALD needs in outpatient cancer clinics highlighted the importance of recognizing language-related needs and care teams adapting practices and available resources to make it work for CALD communities.<sup>9</sup>

Work in other CALD groups has also focused on the triadic relationship between the patient, the patient's family, and physicians.<sup>10</sup> Latin American women who were less acculturated deferred to their families or friends to make treatment decisions, highlighting the importance of familism as one of the most culturally specific values for Latinas. Loyalty and solidarity among members of the family are integral to decision making. Asian and Latino patients are seen to have a higher rate of patient passivity because of cultural norms that respect physician authority.<sup>11</sup> A systemic review of cancer beliefs in minority populations, the majority based in United Kingdom and United States, found low health literacy, fatalism, and stoicism as common themes.<sup>12</sup> Decision making in a systematic review, with a predominant African American minority group, found the themes of spirituality, fatalism, and acculturation to be important in the treatment decision process.<sup>13</sup>

Ultimately, all these cultural beliefs and concepts feed into how patients decide which treatment road they wish to take. Shared decision making models in ethnic minorities have taken into account human values recognized across different countries and the relation between these.<sup>14,15</sup>

As clinicians, we often focus on the disease, with the goal being to get rid of as many cancer cells as we humanly can and prolong our patient's life expectancy while maintaining quality of life. I often feel we require tangible goals which can be measured in time and percentages, hazard ratios, and survival odds at 2 or 3 years. For the patient sitting on the opposite side of the desk, who are only single points on a Kaplan-Meier curve, goals may be very different, shaped by their own cultural values and beliefs. What numerical value can we place on traveling overseas back home, enjoying conversations over family dinners, rather than going to the cancer center for the next cycle of treatment?

My patient had decided his goal was to return home to his family in Vietnam. I saw him in clinic several times, each

time gaining more of an understanding of his decision. I spoke to his partner, we obtained a face-to-face interpreter. We discussed culturally appropriate support groups. He was active in local community groups who provided spiritual and existential support. I enquired about herbal remedies, which he had been on preceding his cancer diagnosis and continued with our pharmacist's approval. We turned to discussing where he was going to be living in Vietnam, potential complications during the flight home, provision of a medical letter, and copies of his tests. He remained uncertain about the prospect of further treatment, that it was hard to access good medical care and did not offer any answers about whether he planned to seek out treatment in the big city hospitals back home. He reassured me he would be fine.

Every time I see a CALD patient, I remember my patient who politely said no, thank you. I wondered if he ever accessed any treatment, how quickly his disease progressed, when and how he died. My initial frustration has evolved into the understanding of how important it was for him to be surrounded by family. I found solace knowing he died with family by his side. The treatment he wanted could not be offered through an intravenous drip or medication. It could only be found in the safe familiarity of family. Every time I see a CALD patient, I try to create a culturally familiar place

for them to be treated and place their decision making amid their cultural beliefs, norms, and values.

The theme of last year's World Cancer Day is "Close The Care Gap." Language, literacy, ethnicity, race, income, education, socioeconomic status, and geographical location are just a few of the factors that contribute to the cancer care gap. We need to have cultural sensitivity in mainstream health care and respect the differences that feed into the decision to accept or decline treatment in ethnic minority groups. Ethnic minorities are defined as nondominant groups, connected by a shared cultural heritage, values, and often language. It is important to note that this is also a relative definition, and my patient in Australia falls into the CALD group, but would be the dominant group back in his home country of Vietnam. Health and illness are not only visceral but also a social and cultural phenomenon. Sometimes, it is recognizing that closing the care gap does not bring us to the same destination, but to walk the road less traveled with them. As the years pass and I reflect on my patient's cancer journey, I have come to understand that as his doctor, it was my job to ensure he understood his disease and treatment options. However, perhaps even more importantly as his doctor, it was my honor to support him down the path he had chosen.

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## AUTHOR'S DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians ([Open Payments](http://OpenPayments)).

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