Medical Xpress

Mongolia has better palliative care than many much wealthier nations

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What comes to mind when you think of Mongolia? My answer, probably like many people's, was vast empty space, those signature round white tents (which Mongolians call gers, not 'yurts' – a word brought in during the country's period under Russian and Soviet influence) and Genghis Khan.

One thing you might not think of is 'a good place to die'. Yet Mongolia is punching above its weight in palliative care, the branch of medicine that supports people with terminal or complex illnesses. Palliative care takes a magpie approach, borrowing from other medical disciplines and addressing a whole range of issues at once, ranging from pain and other symptoms to spiritual, social and psychological support.

In a 2015 survey of global palliative care, the UK comes top, Australia second and the USA ninth. And while the richest Western nations lead the pack, Mongolia appears notably high up, especially considering that it's well down the economic rankings. (It comes 28th in the palliative care survey but ranks 141st for gross national income (GNI) per capita.)

In fact, when it comes to palliative care, Mongolia is performing far better than any comparable economy, and is ahead of several European states with much more developed healthcare systems and greater spending power, including Greece, Hungary and Lithuania. It also eclipses several big economies, including its two giant neighbours, Russia and China.

In little more than a decade, Mongolia's approach to palliative care has become a shining example of doing more with less. But how?

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A ribbon of snow marks the dark hilltops from an overcast sky. The wind bites at the canvas folds of the Tumurbat family ger, their dome-tented dwelling. A few lambs – almost fully grown, too late to be sold – huddle together in a wooden pen nearby, the remnants of a once 100-strong flock. As his aunt and two doctors come into the yard, 18-year-old Dorj Tumurbat stands by the gate, foot up on a kennel. The dog jumps for the visitors, held back by its chain. But Dorj stays put, not even turning his head as they cross the yard and then duck inside the ger. Inside, his father is dying.

Tumurbat Dashkhuu has late-stage liver cancer. Although his illness is incurable, there is something the physicians can do: grant him a death that's as peaceful as possible.

The materials for making a ger have evolved – canvas is increasingly being used for the outer walls rather than animal hides – but they are still constructed to the same basic design. A typical family ger is built around two central wooden pillars (larger ones have more), symbolising the man and woman of the household in harmony. It is bad manners for any visitor to stand in this central, sacred space.

But when Dr Odontuya Davaasuren and her colleague enter the ger, everything is off balance. Enkhjargal, Tumurbat's wife, is holding back tears, clutching a sheaf of prescriptions and other medical papers. The stove is going out. A pool of water is collecting on the linoleum floor, spilling from a washing machine on one side of the tent.

Next to the washing machine is a large fridge-freezer, and wires strung

across the tent's wooden frame lead to a television, DVD player and other electricals. The ger is situated in a capacious fenced compound, with a platform built for a second tent.

The family had been doing well from its livestock business, shifting between the pastures in spring and summer and hunkering down during Mongolia's harsh winter here on the outskirts of the capital, Ulaanbaatar. But with Tumurbat unable to work, they have had to sell almost all their sheep. Enkhjargal has had to take a part-time job in a local abattoir to make ends meet. Diagnosed late, barely a year ago, Tumurbat's cancer has upended their lives. And he is in agony.

The light from the doorway picks out his face, which is stiff with pain. He sits back across a bed, leaning on a stack of tightly folded blankets. He rests his hands delicately on the source of his torment, a bloated, fluid-filled abdomen, a typical symptom of late-stage liver cancer.

The comforting evidence of family surrounds him. At one end of his bed there is a large wooden board propped up on a table and tied to one of the ger's rafters. It's covered with colour photos of big groups of adults and children. To the side there's a small altar with a little figure of Buddha on top and several brass water bowls below, part of a Buddhist ritual to ward off negativity.

I fail to find any immediate positives in this example of palliative care in action. Tumurbat struggles even to answer questions from Odontuya and her colleague Dr Solongo Surinaa. "All I want is to be without pain," he whispers.

Solongo is in charge of palliative care at the nearest district hospital, looking after both in- and outpatients. Odontuya asked her to make this home visit during my trip so I could see how palliative care works for those without medical services on their doorstep.

Mongolia is the least densely populated country in the world, and distance is one of the biggest challenges to delivering any service there, including healthcare. It is just under an hour-and-a-half's drive from the hospital to Tumurbat's home, which is in a semi-rural hillside area – though it is still part of the Ulaanbaatar capital city region. (The Ulaanbaatar region – treated as a province in Mongolia – has a population of barely 1.4 million, but covers an area nearly three times that of Greater London and five times that of New York's five boroughs.)

Tumurbat is being hit by surges of what is called 'breakthrough pain', which burst through the 60 mg/day of morphine he has been prescribed. Two weeks earlier, I am told, he had come home from hospital in a stable condition, his pain under control. The oncologists said the best place for him was here with his family. The local clinic would provide outpatient support, including his weekly prescription of morphine tablets – all covered by Mongolia's national health insurance scheme.

But Tumurbat's condition has worsened in recent days and, as Odontuya and Solongo learn more, it is clear he and his family have not been sure how to react. Enkhjargal has not bought an additional drug, dexamethasone, that had been prescribed to reduce the inflammation around her husband's liver and thereby temper the pain.

And crucially, Tumurbat was not aware that he could take additional, so-called PRN doses (from the Latin pro re nata, meaning 'as the circumstance arises') of morphine beyond his daily prescription to deal with the surges of breakthrough pain. If he were to go beyond four PRN doses in 24 hours, then his prescription would be recalculated and updated.

On this visit, Odontuya – the more senior doctor – acts as a trouble shooter, explaining how to respond to the pain surges, gently soothing

both Enkhjargal and her husband, and providing an impromptu class in spiritual care, advising her how to prepare for his impending death. Enkhjargal is distraught as the two doctors make to leave. Outside she breaks into sobs and buries herself in Odontuya's shoulder. It is a moment some doctors would struggle with, but Odontuya lets her cry before gently pulling back, and then, holding her arms, urges Enkhjargal to prepare for the end.

The doctor's most direct advice concerns Enkhjargal's son Dorj, who was due to start his military service the following week. The family has to talk to the relevant authorities to delay his enlistment, Odontuya tells them. "It is so important that he is there when his father dies," she tells me as we drive back, "to avoid complicating his grief."

Odontuya is more than just a conscientious doctor – she's also largely responsible for Mongolia's rapid progress in palliative care. Spurred by her own father's traumatic death from cancer, she's made it her life's work to campaign for better treatment for people with incurable illnesses. And it's working.

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The treatment Tumurbat and his family are receiving is a long way from what Odontuya was taught when she trained to be a doctor in the late 1970s. Growing up in Mongolia's socialist years, when the country was a satellite state of the Soviet Union, she studied in what was then Leningrad. She speaks fluent Russian. It was excellent tuition, she says, "but we were told simply to treat patients, not to treat them as people. There was no compassion."

The way her father died changed her outlook forever. He was diagnosed with lung cancer the same year she began her studies in Russia, and in Mongolia's health system at the time he was effectively condemned to a

painful death. Not only did palliative care not exist, but it was impossible to get hold of morphine or other opioid-based painkillers.

Less than a decade later, her mother-in-law was struck down by liver cancer, and Odontuya says she too died in extreme distress. What she calls the "psychological pain" of witnessing a loved one in such a state affected everyone in her family, she says.

It was a trauma that many more families have gone through since, because of a steady increase in cancers nationwide over the past two decades, especially liver cancer. The underlying cause was Mongolia's already high incidence of hepatitis – dubbed a "silent" hepatitis epidemic by the World Health Organization – which was exacerbated by frequent needle sharing in the poorly resourced socialist healthcare system.

Government policies made things worse, according to Odontuya and other doctors I speak to, by handing out free vodka. In the economic turmoil that followed Mongolia's independence (after the collapse of the Soviet Union in 1991), the authorities were forced to introduce food rationing. But one thing they had plenty of was vodka, and they added it to every ration. "Each family got two bottles a week," says Odontuya, shaking her head. "It was a very stupid policy."

Mongolia was already a country of heavy drinkers, and alcoholism became even more common in those early years of independence. Precisely how much impact this had is hard to determine, but with already high rates of hepatitis infection, Mongolian doctors believe the increase in drinking contributed to the rise in liver cancer.

But it was this same cancer crisis that helped make the case for developing palliative care in Mongolia. Odontuya started lobbying for the introduction of palliative care in earnest from 2000 onwards. But first she had to come up with the right words. "[In Mongolia] we didn't

have any terminology for palliative care," she tells me as she gives me a tour of the country's first palliative care ward, established in 2004 at Mongolia's National Cancer Center. Pointing out the sign on the door, she laughs: "If you pronounce it wrong, it can sound like our word for 'castration'."

But even with the words fixed, the initial reaction from officials was scorn, she says, as they dismissed palliative care as an "activity for charities". "They asked how they could justify spending money on 'dying' patients, when we don't have enough money for 'living' patients." She answered with her own question: "Would you say this to your own mother, if she gets cancer or some other incurable condition? And I told them, these are still 'living' patients." Even at the end of life, she says, people have human rights.

None of the former health officials I contacted responded. That Odontuya encountered resistance is hardly unique. Palliative care advocates elsewhere have also faced scepticism regarding its value – as much from medical professionals as from bureaucrats. For instance, one US study reported oncologists being reluctant to refer patients for palliative care because it "will mean the end of cancer treatment and a loss of patients' hope".

And for many doctors, palliative care chafes against their default philosophy. As Simon Chapman, Director of Policy and External Affairs for the National Council for Palliative Care, a UK-based umbrella charity for people involved in palliative and end-of-life care, puts it: "There is still a view among many clinicians that [a patient] dying is a professional failure."

Today, Mongolia still has the highest incidence of liver cancer in the world. Many people are diagnosed late, when the disease is advanced and doctors can do little to stop it spreading.

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The Songino Khairkhan district hospital on the west side of Ulaanbaatar has a solidly Soviet feel. Built in Mongolia's socialist period, its walls are so thick they look like they would stop a tank. And the signs around the building add to the atmosphere, written in the Cyrillic script the Russians bequeathed the Mongolians.

Behind the locked door of the hospital's main dispensary for morphine and other opioid painkillers, I am firmly back in the present. There is an air of efficient calm as two staff members work at computers, updating the database on recent prescriptions, while their boss Dr Khandsuren Gongchigav gives me a short tour of their workspace. The security is necessary to meet local and international laws aimed at combating drug abuse, and here they distribute only opioids. There is another pharmacy in the hospital for everything else.

Against one wall is a bulky metal security cabinet, its shelves filled with neat stacks of boxes of tablets. Some contain morphine, the strongest of the opioid family of drugs. It's used for severe pain, including breakthrough cancer pain, because of its fast and powerful effects. There are other stacks – of tramadol, a less potent opioid for what specialists call moderate to severe pain.

There is a lot more to palliative care than pain relief, but experts agree you can't have a successful palliative care programme without it. That means having an effective system for distributing opioids, which both meets patients' needs and satisfies concerns about addiction and abuse. Reforming Mongolia's approach to morphine was an early priority of Odontuya's campaign.

Before the government agreed to reforms in the early 2000s, the rules were highly restrictive and counterproductive. Only oncologists were

allowed to prescribe opioids and at a maximum of 10 tablets per patient – enough for just two or three days in most cases. As a result, people with cancer often died of "pain shock" when their dose ran out, says Odontuya, leading to a widespread myth that the drugs were killing people. Making morphine more readily available has helped educate patients and doctors about its benefits and reduced what she calls "morphine-phobia".

Opioid medications still require a special form, as in most countries worldwide. But a much wider range of professionals can now prescribe them, including oncologists and family and palliative care doctors. This has led to a 14-fold increase in their use in the country from 2000 to 2014, according to Mongolian health ministry figures. Khandsuren is an oncologist by training, and now oversees opioid prescriptions for all the hospital's outpatients. The majority are still people with cancer, but non-cancer patients have become more common.

Every district hospital in the country now has a pharmacy like this one, allowing patients to visit weekly and get all the medication their doctor has prescribed. Nonetheless, in a country so large and so sparsely populated, that still means long journeys for patients in areas beyond Ulaanbaatar or other towns and cities.

Beyond the store cupboard, Khandsuren shows me into a room where they keep garbage sacks filled with empty blister packs. Patients have to hand over the used strips before they can get their next dose. "We do everything here according to guidelines from the United Nations," says Khandsuren, referring to rules drawn up by its specialist drugs control agency, the International Narcotics Control Board (INCB).

Mongolia's achievements have turned it into an example for many middle-income countries struggling with similar health problems but which, for a variety of reasons, maintain much stricter rules on opioid

use. Doctors from former socialist states in particular have been coming to Mongolia to learn from its experience, their mutual past ties to Russia giving them a common language and training background.

The National Cancer Center recently hosted some doctors from Kyrgyzstan, one of the former Soviet states of Central Asia. They remarked on how "peaceful" the palliative care department was, says Dr Munguntsetseg Lamjav, one of the centre's senior staff. In Kyrgyzstan, she was told, it's much harder to prescribe morphine and patients are always crying in pain.

One of the most striking contrasts with Mongolia is its giant neighbour Russia. So tight are the rules there on prescribing morphine and other opioids, I learn, that consumption has actually declined in recent years, according to INCB figures.

There is also a tendency among Russian doctors, many still influenced by their Soviet-era training, to see pain as a problem to be endured rather than treated. It is hardly surprising then that palliative care there remains very limited. But one result is frequent horror stories of people with cancer or chronic pain dying by suicide because it is so hard to get effective medication.

In fact, many governments around the world remain nervous about making morphine more available – and with good reason. Take a look at the USA, which has an endemic problem with abuse and addiction to legally prescribed opioid painkillers. But there are far more Americans suffering chronic pain (at least 30 per cent of the population according to one study) than there are drug addicts. It is all about balancing priorities, Odontuya argues. And so far at least, Mongolia's controls seem to have worked well – its health ministry says there are few reports of people abusing opioid drugs. You hear far more concern about alcohol abuse.

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You don't have to spend long with Odontuya Davaasuren to realise that she's not someone who gives up easily. I have rarely met someone as committed to a cause – except perhaps in a warzone. And there is an element of underground insurgency to her campaign, which she has pursued while also holding down a full-time medical teaching job, working as a doctor and juggling family responsibilities.

Her flip-top mobile phone rings constantly, until she switches it off. Sometimes she sees patients in her own home after work. "My husband has got used to me using our front room for consultations," she says, smiling.

The advocacy and training organisation she established, the Mongolian Palliative Care Society, turns out to be little more than a few filing cabinets and certificates at the back of a basement room in the clinic where she works as a family doctor. The society is an umbrella group of charities and palliative care specialists, including all the country's hospices. Odontuya is the glue holding it all together. "Sometimes I get very tired," she tells me one day. "But I don't think anyone else has the same heart for this."

It has been a quest of relentless government lobbying, made more complicated by frequent political upheavals. There have been nine different health ministers in the last decade, and for each she says that they have had to go and "convince them about palliative care".

It is in the cramped basement room that I first meet Odontuya, on a day when she is using the space as a classroom. She is a professor at the country's premier medical institute, the Mongolian National University of Medical Sciences, and her fourth-year students are here for a session on geriatrics. And she is teaching in English, her third language after

Mongolian and Russian.

I feel some pity for the students because the class lasts over three hours, and it is well past the halfway point before Odontuya remembers to give them a short break. Slackers at the back, I note, have no escape. "Why don't you have any questions?" she demands of a young man who thought he had managed to avoid her gaze. But she is an excellent teacher, and by the end of the class I have learned a lot about diagnosing elderly patients.

Her university work complements her campaigning, because she has also set up a palliative medicine course there. Hundreds of doctors and nurses have now been through the training programme, according to Odontuya – helping to build a nationwide network and reservoir of skills.

She has also built the foundations of a similar international community through her own efforts to educate herself in palliative care. It began in 2001, when she studied palliative medicine in Poland, which was ahead of Mongolia in developing its own hospice network. Today, she is increasingly in demand to provide her own palliative care training, particularly in Russian-speaking former Soviet states. She has recently returned from running a course for doctors in Kyrgyzstan.

For a country that had no palliative care to speak of barely a decade ago, the change has been dramatic. All Mongolia's 21 provincial hospitals as well as the nine district hospitals in Ulaanbaatar have at least five palliative care beds, as well as individual morphine dispensaries. There is also a network of private and charity-run hospices that provide palliative care around the capital city region. Even Ulaanbaatar's prison hospital has four beds reserved for terminally ill patients. The national health service now has to provide palliative care by law.

"It is the government that has made the policy," Odontuya says. "All I

have done is advocate." But I am not surprised to hear from colleagues of hers that I speak to during my visit that she has been dubbed the 'Mother of Palliative Care in Mongolia'. At the country's Ministry of Health they agree. "We have learned a lot from her," says the Director of Medical Services, Dr Amarjargal Yadam.

"In the past, many hospitals turned people away because they were incurable," Yadam says, speaking for the minister, who was away during my visit. "We still need to make a lot of reforms," she adds, "but we are listening to the people." Health is now such a priority, she says, that it is ring-fenced from likely future budget cuts forced by a recent economic downturn.

As Odontuya's students grab their books and rush gratefully out of the tiny classroom, she switches back into her role as evangelist, showing me the many training manuals from Western medical institutes and international health bodies that she has had translated into Mongolian.

And at a time when she was already a grandmother, that meant learning English from scratch – not just to understand the texts, but also to apply for grants to get them printed. She remembers getting the first email from one of her funders, the Open Society Foundations, and then spending the next day going through it with her English-to-Mongolian dictionary. "There was no Google Translate then," she says. "This is how I learned English."

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"I have less pain now" says Batzandan, a 57-year-old film and stage actor with advanced cancer. "But I know I am not getting better." We are talking at his bedside in the palliative care ward of Mongolia's National Cancer Center. In the past, he may not have been given the whole picture, but Munguntsetseg, the senior doctor on duty, says Batzandan

has been told to prepare for the end. "Our policy now is to give patients the full diagnosis," she says.

But 'breaking bad news', as it is often called, is one of the hardest tasks for any doctor – even more so in a country like Mongolia, where any mention of death has long been a taboo subject. There are also particular beliefs about dying on certain days of the week, I learn. "Tuesdays and Saturdays are bad luck," Odontuya says, "so if someone is close to death on those days, families put a lot of pressure on doctors to make sure they die the next day."

As much as possible, they try to work within local traditions and beliefs, not against them, using them to their advantage to put a local face on palliative care. Odontuya often uses a Mongolian proverb in her conversations with patients who are close to the end. It is hard to translate directly, but in essence it speaks of the inevitability of death, and she says it helps "patients to accept the real situation, accept a poor prognosis easily, because it is true that everyone will die someday".

Traditions from Buddhism – the country's dominant faith – have also been a help. When someone dies, a lama, or priest, reads from special scriptures, which is known as "the opening of the Golden Box". The priest can also tell if this person had lived longer or shorter than God intended, explains Odontuya, and "sometimes the lama says [living longer] is because of good medical treatment".

Back on the palliative care ward, Munguntsetseg says she has seen attitudes to death change since the ward was established. "More patients write a will now," she says. "They would never have done that in the past because it would be seen as a bad omen."

The hospital also offers patients what the doctor calls a "reputation treatment service", encouraging them to tell their life story before they

pass away. It began as a way of dealing with patients suffering severe depression, she says, but then they found that other people wanted to tell their stories, to set the record straight. "We had a patient recently who asked his ex-wife to visit, so he could apologise for his past behaviour, and he gave her money too."

Some palliative care patients have responded by drawing up 'bucket lists'. During my visit, I met a woman with terminal cancer who had recently returned from a visit to Lake Baikal (the world's deepest lake) in Siberia, just the other side of Mongolia's border with Russia. With her week's prescription of morphine tablets, she had been able to make a journey that had been "a lifetime ambition".

Before she studied palliative care, Odontuya says she was a "very closed, quiet person", adding that if anyone had mentioned spirituality in the past, "I would have thought it was religion". But a visit to a Polish hospice sparked a "revolution in [her] brain". Then she understood that palliative care is total care, she says, something that covers "all physical, psychological, spiritual and social pain".

The idea of palliative care being holistic can be traced back to Cicely Saunders, the British nurse and doctor who established the first hospice in the UK in the 1960s. She came up with the concept of 'total pain', arguing that it was as important to address the mental, emotional, spiritual and social aspects of patients' suffering as it was to treat their physical symptoms.

Odontuya worries that spiritual matters could still be sidelined by the modernising pull of more clinical approaches. "The Ministry of Health and our university do not understand what spirituality, spiritual pain and spiritual care mean," she says. Still, Saunders's focus on the spiritual side has been an inspiration for Odontuya.

"She lived in modern society, but she thought like a postmodern person," Odontuya says. Saunders was also a charismatic campaigner, and Odontuya seems to be taking on her mantle – you can already see the impact she has had in Mongolia. But she modestly ducks the comparison, saying: "I am just her little finger."

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It is a bright, freezing day in the Mongolian capital. Shards of winter sun reflect off of the nearby crop of glass towers, which sprung up in the city centre during the country's recent minerals boom.

A small crowd is heading towards a giant statue of Genghis Khan on the far side of a square that is named after him. Some people carry placards in Mongolian exhorting the virtues of palliative care, hunching into their coats as the wind stiffens. These doctors, nurses and hospice staff, as well as their friends and family, have come from across the country to hold a rally to raise awareness, part of World Hospice and Palliative Care Day.

In the midst of the crowd is Odontuya, alternating between greeting friends and making phone calls to check the journalists she has invited are on their way. "Always I am doing advocacy, advocacy," she says.

I wouldn't associate Genghis Khan with palliative care, I think to myself, as I follow them towards the statue of Mongolia's famously pitiless founding father. But time is a great cleanser of reputations, and now the man Mongolians call Chinggis Khaan is everywhere – even the main airport is named after him. And his is the square in Mongolia you choose if you want your gathering to have maximum impact.

The municipality had turned down her request for a rally, Odontuya says, apparently claiming it was closed for an event. She decided to show up

anyway. Apart from a wedding party posing for a photographer, there is no sign of anything else going on. As they approach the statue, a guard sees the placards and TV crew waiting nearby, and holds up a uniformed arm to halt the impromptu collective. "This is not allowed," he barks.

Odontuya and two colleagues persuade him to compromise. Workers from each hospice take it in turns to line up beneath the statues, laughing and chatting as they hold up their placards for the cameras. Genghis glowers from above.

Photos done, it's time to head off for a picnic in the hills. We drive up through one of the new suburbs creeping up the hills around Ulaanbaatar, past unfinished developments with names like English Garden and Forbes Mongolia.

The mood is very happy. The care workers laugh at the pretentious names. They laugh at everything. The jokes continue as they unload picnic baskets from the cars and carry on up the hill, past a park filled with concrete gers for tourists.

After lunch, there is music, dancing and games – and then an awards ceremony, with Odontuya handing out prizes for the best hospice and palliative care workers of the year. And then there is a prize and a cake for her too. "We love her," says one young hospice worker, nodding her head towards Odontuya behind us.

Another hospice worker brings out his guitar and starts up a group song. Odontuya peels away to do a couple of television interviews. That evening all of Mongolia's main TV channels run a story about palliative care.

Odontuya says that they get together like this every year because the hospices are spread so widely across Ulaanbaatar she may not see some

staff for months. "I remember going to visit hospices in China and Singapore," she says. "They have far more resources than us, but they don't have this atmosphere. We are poor by comparison, but we love each other. We are a family."

It is, I realise, a theme that permeates all that Odontuya does. From the personal experiences that put her on the path to becoming Mongolia's 'Mother of Palliative Care', to the way she practises it, 'family', in every sense of the word, is a guiding spirit.

After I return from Mongolia, I ask my translator to call Tumurbat Dashkhuu's family and find out what had happened. He died at home a few weeks after my visit, in his ger, with his family around him. And, after following Odontuya's advice to postpone his military service, his son Dorj was there too.

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