The Lost Children of Myanmar

They are children. They have cancer. Most of them could be saved by science and die because of a lack of transport. A Portuguese national has founded an NGO to take them to where they can get treatment. He's making a difference, while the world turns its back on the impoverished victims of childhood cancer, set to increase by 30% in the coming years. Notícias Magazine's reporting team went to Myanmar in order to show people the lives of children like Thiri Win, the girl with the sad eyes. Saw Min Htet Oo and Saw Kaung Maing, the unlikely friends. Kaung Sithu Tun, the brave one. Or Ma Thiri San, the survivor. To show how they are lost. And how they can be recovered.

By Isabel Nery (text) and João Carvalho Pina (photos)

Ko Min Min laughs and points at the footprints left behind by bare feet in the mud. To get home with his 3-year-old daughter he has to row along the arteries of the Irawadi river, the one with water levels that rise during monsoon season to reach the houses in the village, Kyon Pati, and which crosses Burma from north to south.

He laughs at my boots, recommended by local doctors concerned about venomous snakes. I end up imitating him, not just the footsteps, but the laughter. The people of the rivers that crosscut the rice paddies are well acquainted with the natural world that inundates them. It belongs to them. It's on their side. We're the ones who are strangers.

Despite the boots, the truth is that more than lightning (there's talk of a girl being struck in the rice paddies), hemorrhagic fevers (they're expecting an outbreak of dengue), attacks by crocodiles (included in the local demographic) or the fangs of a venomous snake, more than all this, what brings our reporting team to the fields of Myanmar is this Burmese child forced to travel nine hours after being subjected to defence-reducing chemotherapy treatments at the Children's Hospital in Yangon.

Travelling is a poor euphemism when it refers to sitting in a taxi for an hour (from the hospital to Hlaing Thar Yar central station), followed by three more on a bus which is serviceable, but packed with people – and you could say the same for germs. Added to this is a vehicle that looks to have done as much travelling in time (backwards) as it has on the roads. And then a wooden vessel coming from Einme, carrying as much fruit, tobacco and tubing, as travellers from these parts. Among them, a young girl with a rare type of cancer, who only the day before was receiving a blood transfusion and

chemotherapy. After eight hours of bumps, white knuckles and relieving ourselves in holes, there is still the canoe to come.

We travel down an aquatic motorway amid giant vegetation – extreme like everything else – and the green geometry of the rice paddies, with the right to a tingling of fear – despite literally living part of the year in water, the majority of inhabitants cannot swim – of being sent overboard by a passing canoe.

The fragile girl travels hanging from the neck of her father, a widower at the expense of his fourth child. Even with only one arm free to cuddle her, he now restores a confidence in grownups that was lost during months in hospital. The tumour affecting her liver has tinged her eyes the brownish-yellow of a Tiger's eye gemstone.

Thiri Win represents just one of the more than 700 Burmese families whose 1300 journeys have been paid for by Please Take Me There, an organisation supported by World Child Cancer (WCC) and conceived by a Portuguese national, Fernando Pinho, who decided to make providing assistance to children with cancer his mission after witnessing his brother survive the illness. Fernando, 41, knows: he would be unlikely to still have someone to call a brother if, by a misfortune of karma (to use this region's prevailing law of moral causality), he had been born in Myanmar and not Portugal.

In this country in the southeast of Asia, a child with cancer requires an average of 12 hours – and sometimes even days – to reach the hospital in the old capital, the only one with effective oncological treatment. Able to be treated in over 80% of cases in developed countries and only 10% in regions like Myanmar. Ironic to conclude, as Fernando did, that it would take only something as rudimentary as a taxi to achieve less miserly survival rates.

EASTERN CROSSINGS

We access the home with a thatched palm roof – the family's only property, aside from their half of a pig shared with one of thirty neighbours in the village – by means of a wobbly ladder. Feet should tread lightly on the fine bamboo cane floor, ill-prepared for bodies nourished on a Western diet. Large gaps provide a glimpse of the muddy water that runs beneath our feet.

As soon as we arrive, grandmother Daw Htay, 61, widow for 11 years, tugs me with her arm – something like arthritis prevents her extending the fingers of one hand without the help of the other – to invite me to sit on the mat beside the Buddhist alter, decorated with Christmas ribbon, the most honourable spot in the house. She wants to tell me about how Thiri Win's eyes led the family to go

searching for help. First from traditional healers, then at the Hospital in Yangon, the country's most populous city. It's the third time they will be calling upon the medical services with the support of *Please Take Me There*, which covers the cost of transport, identified by the WCC as the principal challenge facing sufferers of childhood cancer in the country.

What tinges her eyes has already spread to all the cells. The doctors use complicated words like leukocytosis, which they admit the families don't understand, but are unable to explain more clearly. Thiri Win's father and grandmother believe the illness is treatable. It would require no more than a transplant, a reality in countries like Portugal, an impossibility in Myanmar.

Despite her granddaughter's fear – we only hear her exchange whimpering for words during the bus ride spent on her father's lap, stunned by the hordes of bright-red monks, trees emerging from the water, gigantic Buddhas between the green needles of the rice paddies, and all that's sold by the side of the road, from coconut water, to quail eggs and all kinds of fruit – Daw Htay believes the hospital was the right choice. "We're doing everything we can. If she doesn't recover, then that's Karma. Destiny has the last word," she says, without taking her eyes off the knife chopping water spinach to feed the pigs.

I am unable to forget the words of the specialist in Paediatric Oncology at the IPO (Portuguese Institute of Oncology) in Lisbon: "A patient undergoing chemotherapy is always immunosuppressed. They shouldn't use public transport. The Portuguese state funds journeys by ambulance. They shouldn't so much as go to the beach. Even sand carries germs."

Recommendations that appear to come from another world after having watched this family travel since when day was still night, drinking water from a communal cup and dodging gobs of betel (leaves chewed with Areca nuts), which provide energy and cheat hunger, but colour the mouth blood red.

After diagnosis, 44% of parents can no longer work regularly. Transporting a child for treatment costs an average of €18 – and the majority of families live on less than €2 per day. Many give up.

UNLIKELY FRIENDS

Returning to the hospital building I find I am more tolerant of the smell of jackfruit (forbidden on many premises due to its pestilent odour) and ready to receive the gentle smiles that await us in each corridor.

The journey through the hardship of the Asian southwest has provided me with other eyes with which to see the Children's Hospital in Yangon. If I were to arrive now for the first time, perhaps I wouldn't

notice the walls spattered with red, in spite of the signs prohibiting the chewing of betel. Or maybe I'd be less moved by the parents who sleep out in the open (more than 60% according to a survey by Please Take Me There), sharing a space with the rubbish and the rats. Or make nothing of the sterile gauze cut with kitchen knives and the consultations provided in the waiting room, where forty children arrive daily.

My gaze had already come to settle on an eleven-year-old boy, his last birthday celebrated in hospital. A brown *longyi* covering what was no longer there, forced to accept his mother's lap when, after a couple of moments, he could no longer bear the flamingo pose. A bone tumour diagnosed too late – as almost always happens in this country – had cheated him of a leg. It left behind the tranquil smile. And the dream of being a pilot, confesses Saw Kaung Maing, pretending to fly the TV remote. "I can't play because I no longer have a leg. But I'm going to fly planes, with or without the leg."

The serene certainty, touching, produces laughter (perhaps nervous) from the bed in front of us. Cheeks decorated with the yellow powder extracted from a root that protects skin from the sun (thanaka), expressive smiling eyes, Saw Min Htet Oo, 10, sees his mirror image in the friend gained in hospital. Leg in plaster, identical diagnosis, though less advanced, there is already a date set for the amputation. He takes refuge in wisecracking**.** And friendship: "In another life we must have broken someone's legs and that's why we're here. We must have been friends. Or brothers."

Saw Kaung and Saw Min aren't the only unlikely friends at this hospital. Unlike the other children, Ne Ne, 5, daughter of the accountant for Please Take Me There, runs through the corridors without any of the hospital trappings. She's more familiar with the world of children who suffer and die than with the other one, in which children outlive their parents as the good laws of nature decree. She has even imported the vocabulary: "When they expire [term used by the professionals], I feel sad," she admits, eyes glued to the floor. Accustomed to accompanying her mother since she was little more than a year old, Ne Ne claims she has more friends in the hospital than at school.

The three children met here, amid the cries of pain, the empty beds of those who until yesterday still wanted to play, the children with eyes emptied by tumours (generally, retinoblastomas, curable in the West, while here they kill and blind), and the amputated limbs. They don't know about unlikely locations for friendships. "When we get out of here we'll play over the phone."

TO GO AND COME BACK = TO SAVE

To amputate the leg of someone who still has such a long road ahead is to deny them the very right to a childhood. The sacrifice brings the prospect of a fifty percent chance of survival, at best. But this

doesn't cause Aye Aye Khaing, the person in charge of the emergency department, to waver. Especially because those who never arrive here, the majority, are summarily robbed of any chances. "We have to do everything. Even if they don't survive, they may live longer. We can't give up on these children. The principal objective is for them go home and come back. If they didn't give up, we could save another 12 percent."

Going and coming back could be the difference between dying later and dying sooner. Between receiving palliative care and leaving the world in pain. The partnership between WCC and Please Take Me There aims to mitigate the number of people giving up. "We know that 25% of families abandon treatment because of a lack of money for transportation. The biggest frustration is when they don't come back. With the help of NGOs we have reduced this number to 11 percent," explains the specialist in Paediatric Oncology.

After the arduous journey on ramshackle buses and perilous canoes, we know that not giving up on treatment is a tall order. Even more so in the largest country in continental Southeast Asia, where electricity only reaches half the population and the majority admit to not having known of the existence of childhood tumours. "When they told me my daughter had cancer, I didn't believe it. I spent the whole journey crying because I thought she was the only child with the illness. At the hospital I realised she wasn't. I was relieved," confesses the mother of Ma Thiri San, a 6-year-old girl who has spent the last three in treatment and is considered a success story.

So much so that the family have moved from the village where they lived, more than a day away, to Yangon. Even so, it takes 3 hours to reach treatment. Little fingers always drumming on her skinny legs, Ma Thiri San has already decided: she wants to be a doctor. "To stick needles in other children." Until then, the dream is rehearsed, in a forgivably vengeful spirit, upon parents and friends.

Portugal records around 300 new cases of childhood cancer per year. In Myanmar there is no register of paediatric oncology. We can only estimate, in accordance with the South Asian Journal of Cancer, between 1,500 and 2,800 cases for a population of 53 million. The rate of childhood cancer is similar in all corners of the world (SEE SIDEBAR). What vary are the weapons available to fight against it.

NO RIGHT TO FORGET

We were in the second week of Paediatric Oncology in Yangon. I figured the report should reach the screams on the fourth floor. I believed I was prepared.

All reporters have their limits, and mine, it appears, is watching a 3-year-old boy having his spinal medulla perforated by a six-centimetre needle – a procedure in which any mistake could be fatal – in order to perform a lumbar puncture. Without anaesthesia.

It wasn't so much the clinical procedure – as a medical journalist I've witnessed a lot – but the plea that nobody in that cramped glass room could acknowledge. "Hold me, daddy! Hold me!" was all that Kaung Sithu Tun was asking, while three adults, including his father, forced him against the hospital bed. In that moment, in that hour, being a good father meant refusing the embrace. And I can't think of anything more painful than refusing to embrace your terrified child.

I take advantage of the moment the nurse opens the door to the room to slip away. The veranda, crammed with drying racks, pots, oxygen tanks, rolls of gauze and basins, seems like some kind of alternative. But almost instantly I walk into a washing line of fluttering yellowed sheets with a tear in them. It's through this slit that they insert the needle between the vertebrae to reach the medullary centres of the children with cancer, who are weak and weakened.

A change of scene seemed advisable. The grey sky of the Asian monsoon is speckled with crows. I had doubted whether it really was children's cries I had been hearing, or just the cawing of these black birds, considered ominous in other realms. In flight they did not seem worthy of a hospital version of Game of Thrones, but then there was their chosen perch – the drip stands parked on the veranda. Some acting as hangers for surgical masks, waiting to be reused.

A symbol of death and bad luck for Westerners, in Asia the bird is an auspicious sign. An ideal time to invoke some blessed perspective. According to the World Bank, in 2014 Burma spent only 2.3% of its GDP on health (9.5% in Portugal). We are in the best children's hospital in the country, which relies upon just two centres for paediatric oncology, in Mandalay and Yangon. This is the one elected by all those who can't pay for health services in neighbouring Thailand, which boasts two hundred paediatric oncologists, while in all Myanmar there are only seven. "We began with three beds and today have seventy-five, of which sixty are for paediatric oncology. But we need a hundred. And more doctors."

The lack of human resources is, for Aye Aye Khaing, founder of this unit in 2002, the biggest issue. The meagre salary of less than €300 leads 15% of clinicians trained abroad to remain there. "I only came back because my mentor told me I'd be needed more here," confesses the doctor, who worked for three years in the United Kingdom and trained in Singapore.

Even so, the patients here don't lie in pairs, as happens in the building opposite, with 750 internees and 550 beds. There are now patients who come back to show the hospital to their own children or trainee doctors. Lives are saved and suffering is reduced, even if at different rates to the West. While

admitting that the punctures can be traumatising – “on a pain scale of 1 to 6, a puncture is level 4” – there is nothing more Aye Aye Khaing can do to help. For the whole of the Yangon hospital there is only one anaesthetist.

In Portugal, there is no extraction of cerebrospinal fluid from children without anaesthesia, assures Ana Lacerda. “The treatment of an oncologic illness leaves after-effects similar to the post-traumatic stress of war. For punctures, children are put to sleep with a drug that causes amnesia so they won’t have any memory of the procedure.”

In Myanmar, children with cancer do not have the right to forget.

MUSICAL DIARY

While it may seem strange to Westerners, the suffering described here is actually synonymous with progress. Without long and arduous journeys there would be no treatment. Without pain there would be no hope, much less survival.

The director of the WCC programme, Piera Freccero, recognises that much has been done since the Portuguese national committed himself to this cause, saving lives (simply) by providing transport and completing the hospital team with three more professionals paid for by the NGO: “We began to notice the difference a few months after Fernando’s project started.” And it wasn’t only families who became less hopeless. “The professionals themselves, seeing someone putting in so much effort, changed their attitudes. We’ll be taking the software for case management and the transportation solution he devised to other countries.”

The campaign to raise funds that saw Fernando spend three days at Lisbon airport with public figures, in 2016, made a lasting impression on Luísa Sobral. So much so that the singer decided to travel to Myanmar.

On the night she spent at Lisbon airport, Luísa, sister of Salvador Sobral, wrote, with the ease for which she is renowned, the song “Please Take Me There”, which she offered to Fernando’s NGO as their anthem. It’s this song that kicks off the improvised concert on the top floor of the Burmese hospital, which was a ministry until the capital moved from Yangon to Naypyidaw in 2006. Won over by the tender voice of the Eurovision champion, the audience of wheel chairs, crutches and bandaged catheters quickly dissolves into laughter upon hearing Luísa Sobral imitate the sound of a trumpet. “I’d already been to the IPO. But here they pay the price for being unlucky with where they were born. When I spent the 24 hours at the airport, I was left thinking about how I could help. Some cases

affected me more because they needed transplants and my own brother is waiting for one. In Portugal, many of these children would be saved."

With no assurances about the impact of her presence in this distant land, where she visited the homes of families, Luísa holds on to the power of music. "It's universal. For me, songs are like a diary. The anthem I composed has a story, which I can tell at a concert, and in that way raise awareness of the problem."

THE EXTREMES THAT REMAIN

Outside Yangon, families come out of their houses just to look and point at the long strange white creatures. They laugh. And, of course, request selfies.

Receiving a stranger is an honour. For cultural reasons – the more visitors, the more luck a family will have – but also for political ones – the country lived under one of the most closed off dictatorships in recent decades and tourism is still something of a novelty. We can't, therefore, turn down the offer of dinner from Thiri Win's family. Sitting on the floor, before a low wooden table, we receive the bowls of white rice, scrambled eggs, fried peanuts and tea (a colonial legacy of the British, in the country until 1948) prepared by Daw Htay, crouching beside a fire stoked on rice husks.

The language has a vibrating sonority, characters that are round and gentle like the people, but I don't know any of the almost one hundred dialects. We communicate with gestures. I eat until the last grain of rice, but Daw Htay keeps pushing little bowls towards me. I tell her she reminds me of my grandmother, who has just turned 98. She smiles, puts her hands together and bows in thanks.

Happy at the presence of strangers, a presage of abundance, Thiri Win's family invites us to sleep in their cane house. We can wash in the muddy water like the children, who soap themselves in front of everyone when they arrive home from school, or be taken by canoe somewhere we can have a kind of shower.

We've already stretched out our mats when the message arrives from the village administrator: the law does not permit strangers to spend the night in private homes. There's nothing left for us to do but bow in gratitude. *Jesutimbaré*. And repeat the learned farewell. *Da Da*.

We return via the same Venice of rice paddies by which we arrived. Now with no colour, beneath the intransigent night, nor laughter at how strange we seem. Within the silence of the river Einme, we are reconciled with the bitter extremes and the botanical extremes. The sweet extremes and the spicy extremes. We leave behind the cries of punctures with no anaesthesia and the doubled-over laughter

at the antics of heroic parents. The misery of a stilt house and the sharing of plates of rice. The inadequate hygiene for the immunosuppressed and all that's left to do with so little.

Thiri Win, Kaung Sithu Tun, Saw Min Htet Oo, Saw Kaung Maing and Ma Thiri San are characters from a true story. All they ask for is a different ending. And the – inconvenient – truth is that they could have it.

Sidebar (900 char): An invisible illness in poor countries

Poverty masks cancer. Because of a lack of diagnosis (80 to 90% of cases) and because of "competition" from other diseases. According to Lancet Oncology, 84% of childhood cancers "occur in low-income and medium-income countries, where 90% of all the world's children live." In Portugal, cancer is the second leading cause of death in adults and the first in 5 to 14 year olds, but the World Health Organisation (WHO) reminds us that, in South-East Asia, the death rate for infection and transmittable diseases is 18 times higher than it is for cancer. A scenario that is becoming increasingly complicated, as emphasised by the journal of Clinical Oncology: "In low-income countries childhood cancer is expected to have risen 30% by the end of the decade." And it is in these territories that we encounter "less than 5% of global resources for treatment." Being the most populous continent, the 80 thousand annual estimated diagnoses in the region of Asia "represent 50% of cases of childhood cancer across the globe."

Text translated by Victor Meadowcroft