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Fear, loathing and redemption

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As a leper community, the remote mainland village of Ma Chan was shunned by the outside world for almost 50 years. Now free from the disease, its scarred residents remain condemned by poverty and prejudice to a life of hardship. Photojournalist Steve Cray

Xun Nuo stares into space as he ponders a question that has been put to him. The air is difficult to breathe and, at an altitude of 3,000 metres, it's a bitterly cold November day. His audience shuffles to keep warm while awaiting his reply.

Xun is just 34, though you would never believe it. The harsh winters and primitive living conditions in the village of Ma Chan, at the eastern end of the Himalaya mountains, have taken their toll. Weather-beaten and leathery-skinned, the village chief looks at least 10 years older, although he is in better condition than many of his less-fortunate comrades. For this is a leper settlement and its inhabitants not only bear the disfigurements of the disease but are outcasts, shunned and feared by society at large.

Even assuming you can find a driver prepared to bring you here, Ma Chan (place of the horses) is difficult to get to. The remote outpost is off-road between Qiaotou and Zhongdian, in Yunnan province, western China. Besides the painkillers occasionally provided by the government and charities, Ma Chan has few of the medical aids you'd expect to find in a village of its size, and no doctor. The villagers can't hide their injuries, most of which are the result of a disease that eats away at nerve-endings and skin; others are caused by the harsh living conditions. Eye disease, crippled joints, loss of limbs and distorted and disfigured faces, hands and feet are just some of the more obvious afflictions. Less visible is the damage done to villagers' lungs by wood-burning fires lit in tiny rooms

that have no flues, chimneys or other ventilation. In winter, it is so cold, the villagers say, they rarely venture outside.

Xun was 17 when his family, who live 90 minutes away, in Zhongdian, sent him to Ma Chan, in keeping with the policy at the time of quarantining leprosy patients in isolated communities.

'I was bitter and felt betrayed when I was first sent here,' Xun says, recalling how friends and family noticed his appearance changing as the disease took hold. 'My eyebrows fell out,' he says, adding that he also suffered from joint pains. It took two to three years of treatment with antibiotics before he was cured, but many more years

before he was given an 'exit certificate', declaring him fit to return to the community.

Not that Xun would abandon the village that was once his prison. For many years he, as village chief, was the only person allowed to leave Ma Chan. Official policy towards leprosy patients changed in 2000, allowing them to be treated in their hometowns rather than cast out into separate communities. But by then Xun had met his wife, Qili Lamo, 39, who contracted the disease when she was 25, and Ma Chan had become his home.

'I couldn't leave here now,' he says, flanked by village elders. 'I am too emotionally attached to the village. It is one big family.'

In Ma Chan on the day we arrive are 17 students from Ma On Shan's Li Po Chun United World College. The Hong Kong students are on a mission to paint village houses as part of the school's 'China week' programme, a scheme designed to provide adventure for the youngsters and help for the less fortunate. The multicultural group is accompanied by principal Stephen Codrington, who visited the village a year ago to help build a toilet block. In addition to offering practical help to the villagers, Codrington hopes the visit will help to erode the social taboos surrounding leprosy.

About 60 adults from six ethnic groups live in Ma Chan, down from 200 when it was first built, in 1959. Xun says some residents have died while others, lucky to have escaped serious disfigurement from leprosy, were taken back by their families after the policy change. Although all the remaining villagers have been cleared to leave, poverty and the fear of ostracism keep them here.

'They are not prevented from leaving the village,' says Xun, 'but they will be rejected by other people, even their families.' He adds that even local doctors refuse to tend to their injuries. 'Doctors refuse to see them because they are so scared of leprosy,' he says.

Not all the villagers are former leprosy patients. There are nine married couples in the village, with 10 children, eight of whom have been sent to private boarding schools in Kunming and nearby Lufeng in the past year with the support of charity Caritas Macau. Two pre-school children remain in the village and Xun is concerned about their education. Ma Chan once had a school but it closed when the only teacher prepared to visit the village stopped doing so.

Now that charities are supporting the hamlet, Xun is determined to make sure the children do not suffer the same stigma as their parents. 'I want to see all our children educated and able to move to the city,' he says. He no longer thinks of Ma Chan as a leper colony. 'I think of it as an ordinary village.'

But it is a village cut off from local trade and most of the outside world. Residents have had no choice

but to learn to be self-sufficient. Although the local government gives 300 to 400 catties of rice to each person every year and there are occasional donations of tea, eggs and meat, villagers survive by growing root crops in summer and eating dried foods in winter. They eat chicken and pork 10 times a year but their staple diet is turnips, eggs, other vegetables and rice.

The last person to join the community was Ding Zhu, 26, who contracted leprosy five years ago.

An orphan, he was sent to Ma Chan after being rejected by his own village. Now cured, Ding, who

is uneducated and has only basic farming skills, considers Ma Chan home. 'I would leave if I could but I don't have any money and I would be discriminated against,' he says. 'No, this is my home now.'

The remote, tough existence is perhaps hardest on the young adults whose parents were leprosy sufferers. Although they've never had the disease, these twenty-somethings have been as isolated from the modern world as their shunned elders.

Zhang Liying, 21, looks almost fashionable in her woollen hat and denim jacket. In stark contrast to most of the villagers, the pretty young woman would not look out of place in image-conscious Shanghai. But, uneducated and with a four-year-old son, Qili Nima, to raise, she is trapped in Ma Chan. Zhang had no schooling until she was 17, when she received two years of primary education from a teacher supplied by Caritas. 'If I had the opportunity I would like to leave the village and study to become a doctor,' she says shyly. 'But I don't know how I could do that.'

For the visiting school pupils, the first hurdle they faced was finding drivers prepared to make the 90-minute trip up the mountain then drop them near the village. Now, they must scrape years' worth of soot from villagers' walls before they can start painting.

But the DIY is only a small part of why the students are here. Their major aim is to break down barriers and prove there's no reason to fear the former lepers.

Speaking at the end of a strenuous day, Codrington says: 'Lepers in China really are the most outcast group in society and I think what we're doing in a broader educational sense is to overcome those stereotypes that people have.'

'The last time a resident came to the village was about six years ago. No one has ever caught leprosy within the village. They've all been cured and they all have their exit certificates. They could leave if they wanted to. So we asked them the obvious question: 'Why don't you want to leave?' It was partly because of poverty - they've had no way of earning an income and therefore have no marketable skills in the outside world - but the big thing was the prejudice.'

'Because of their physical disfigurement, they know they'll be outcast in society - and that even includes their own families. So that's the real thing that traps them here: the ignorance of people.'

'I hope that we've been able to do something to overcome that. But obviously there is a long way

to go because these people have virtually made themselves prisoners in the village because of

the discrimination and stereotypes that people outside have.

'I think that's incredibly sad.'

Leprosy, also known as Hansen's disease, is an infectious ailment caused by mycobacterium leprae, which invades human nerves and causes a range of skin problems, including loss of feeling, paralysis of the hands and feet and disfigurement of the joints.

It is easily diagnosed and treatable with multidrug antibiotic therapy (MDT).

The World Health Organisation has made MDT freely available to all patients worldwide since 1995.

At the start of this year, there were 219,826 existing cases,

according to data from 115 countries. There were 296,499 new cases last year, down 27 per cent on 2004. The average annual decrease in the past four years has been about 20 per cent.

Most countries have eliminated the disease, but it is still prevalent in some areas of Angola, Brazil, Central African Republic, Democratic Republic of Congo, India, Madagascar, Mozambique, Nepal and Tanzania.

Improving detection and fighting social taboos is important. In the past, patients were considered to be 'unclean' or 'cursed'. This led them to hide their condition and avoid seeking treatment.

Sources: WHO and Wikipedia

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Suffering in confinement

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Steve Cray

Ma Chan was built in 1959 to accommodate leprosy patients in line with government policy at the time that all those suffering from the disease should be confined. Once there all except the village chief were forbidden from leaving the village.

Chief Xun Nuo, 34, said there were originally about 200 people in Ma Chan but there were now 60 from six ethnic groups. Some left after gaining discharge certificates, others had died. The remaining villagers were trapped by poverty and the threat of ostracism.

There were nine families in the village with 10 children, eight of whom had been sent to private boarding schools in Kunming and Lufeng.

The local government provided painkillers and 300 to 400 catty of rice to each villager every year. There were also occasional donations of tea, eggs and meat. Villagers grew root crops in summer and ate dried food in winter and chicken and pork 10 times a year. Their staple diet was eggs, vegetables and rice.

Since 2000 it had been government policy for people with leprosy to be treated in their own villages which meant Ma Chan will not be receiving any more patients, Mr Xun said. The last person to join was 26-year-old Ding Ju, who contracted the disease six years ago.

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The prisoners of ignorance

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Yunnan lepers can't leave their village even though they've been cured. A group of HK students visited to help, accompanied by Steve Cray

IT WAS A SOMBRE group of Hong Kong students who met up for breakfast at 7.15am in a hotel up in the mountains in western China recently.

They were tired from a gruelling trip on the overnight bus from Kunming to Lijiang the previous day and frustrated that the carefully laid plans for their annual China week seemed to be going horribly

wrong.

The 17 students from Li Po Chun United World College, Ma On Shan, and their principal Stephen Codrington, had spent the previous afternoon and evening carrying out a damage limitation exercise.

It was also cold, especially for those acclimatised to Hong Kong weather. And it was about to get a lot colder. For the group was about set off further up the east Himalayans to about 3,000 metres to spend a couple of days in a lepers' village.

What Dr Codrington and his students didn't know as they ate their breakfast that morning at the Yi Xiang Hotel, Qiaotou, was that things were about to get a lot worse.

It had all started so well. Plans for the international college's China week were always made well in advance and Dr Codrington and the only second-year student in the group, Chris Sykes, 18, from Canada, had been to the lepers' village, Ma Chan, the year before, where they helped construct a toilet block.

The plan was to lead the group of 16 freshers on a new campaign to whitewash the inside of the villagers' houses and get to work on the details of an already advanced plan to provide a teacher for the village children.

The college's Global Culture Action Team, headed by Chris, had spent the best part of a year exploring the practicalities of sourcing and funding someone to overcome the phobia about leprosy.

Central to the students' plans were their go-betweens, Australian Margo Carter and her Nepali husband Sean who had worked with Dr Codrington the previous year. Ms Carter runs the Gorged Leaping Tiger Cafe in Qiaotou, about two hours' drive from Lijiang, and was to provide accommodation, arrange transport, source DIY supplies, prepare food and liaise with the village over the painting.

And that is where the problems started.

When the group arrived in Qiaotou earlier this month, they found Ms Carter and her husband had shut up shop and disappeared. There had been an accident in or near the cafe and the victim had to be taken to hospital in Lijiang. All attempts to contact the couple had failed, which meant no accommodation, transport, food, paint, tools or village liaison.

That afternoon had been a mad scramble to rearrange the tight budget to cover hotel and food bills, buy paint and other supplies and, most difficult of all, find drivers at short notice who were prepared to go anywhere near, let alone into, the lepers' village.

Three taxi van drivers agreed to do the job, except that they hadn't been told where they were going.

So the students' first job after breakfast on Wednesday was to explain they were headed for a lepers' village. Two of the drivers wanted to pull out but were persuaded to make the trip by a combination of extra cash and an agreement they could drop the group 100 metres from the village.

Two hours later, the students arrived - to some disconcerting news.

Although the villagers had been told the group was arriving, they weren't sure when and said their pressing need was for roof repairs and not a cosmetic paint job. And to make matters worse, the year-long plan for a teacher was about to collapse. The children had been rescued by Project Grace in Kunming and the Catholic charity Caritas

in Macau and sent off to private boarding schools in Kunming and Lufeng. There had been a communication breakdown.

Nothing immediate could be done about the roof but the villagers were eventually persuaded that they did need their walls painted after all.

The students soon found that it was a lot harder than they bargained for though, with layers of soot on the walls accumulated over years from wood burning stoves without ventilation. It took hours of scraping to get the black dust off only to discover that the residue reacted with the paint, turning it pink. In addition, there were no face masks and the students found themselves having to brave plumes of soot and dust. It soon became clear that this was a two-day job and a planned hike through the beautiful scenery of Leaping Tiger Gorge would have to be delayed.

In addition, the group discovered that the toilet block built the previous year had been plumbed into a spring that worked only in the rainy season, leaving it high and dry the rest of the year.

It was at this point, though, that things started to pick up. Once the villagers saw their homes brightening up they began to show their appreciation and were even mucking in by the end of the day.

It was a tired group of students who made it down the mountain that night for a debrief over dinner.

Peter Akkies, 17, from the Netherlands, was upbeat about the fact that improvisation had saved the day but had found the DIY challenging. 'The painting was pretty tough at first because we had to mix all the paint which proved to be problematic, it was either too liquid or not liquid enough,' he said.

Diego Terrero, 18, from Venezuela, was troubled by some of the crippling effects of leprosy. Even though the villagers had been cured, they were left with permanent injuries. 'I saw an old lady without a leg and found that quite shocking,' he said.

Angad Pheheja, 16, from India, was less than impressed with hygiene in the village.

'I saw buckets of food that looked quite stale and there was meat that looked like it was there for decades,' he said.

Hongkongers Brian Lo Ka-chung and Felix Lau Ka-hei, both 17, were impressed that the taxi drivers had gone all the way to the village and one even helped with translation.

'On the way back they told us that taking us there had broken their stereotype because they saw that the lepers were not that horrible. They said it wasn't that scary anymore,' Brian said. Felix added: 'Our taxi driver told us they were so impressed with what we did and that we were willing to get involved and not afraid of getting dirty and making contact with the villagers.'

The villagers' reaction to the painting had made Mike Schoenleber's day.

Mike, 17, from Missouri, US, said: 'When I first got to the village and saw all the problems we were facing, I didn't really feel that we were accomplishing anything, almost in fact that we were hurting the village, but about midday one of the women whose rooms we were fixing up walked into the room and her face lit up. She got a big smile on her face and just put her thumb up in the air and started saying hao, hao [good, good] and all of us got so excited and our

spirits totally turned around.'

Chris Sykes was philosophical that the plan for a teacher had come to nothing. 'In a sense it is disappointing that this project we've been working on isn't really one that's needed or a necessity. But in another way, it should be something that we're happy about, because what we were trying to do has already been accomplished and well beyond anything we could have ever imagined. The children have been sent to a private school in Kunming which is way better than a teacher being sent to the village,' he said.

But it was Dr Codrington who summed up the real lesson of the day. 'We've all learned a lot of useful lessons about improvisation and about the need to adapt and rise to the challenges,' he said. 'I really hope that one of the lessons you learn from this China week, that you carry through the rest of your lives, is the skill of being able to adapt and improvise.'

And the real achievement had nothing to do with DIY, but rather with changing attitudes.

'Lepers in China are the most outcast group in society and I think what we're doing in a broader educational sense is to overcome the stereotypes that people have,' he said. 'They've all been cured and all have exit certificates. They could leave if they wanted to. So we asked them the obvious question: Why don't you want them to leave? It was partly because of poverty but the big thing was the prejudice.

'Because of their physical disfigurement they know they'll be outcasts in society and that even includes their own families. So that's the real thing that traps them there - the ignorance of people.'

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