



Zahra, left, who was abandoned by her family because of the stigma, lives with Fatima in a leprosy hospice

Their disease can be cured but leprosy patients face a lifetime of rejection and heartbreak

As the number of cases rise, doctors in Afghanistan fight to end stigma attached to the illness, reports **Jerome Starkey**

When Zahra hobbled back to the hospice she was carrying a hand-written letter from her son-in-law which she didn't know how to read. Her doctor deciphered the scrawl — and it broke the old woman's heart.

"He asked her not to visit again," Dr Ali Mural said. "He said that people in the village were scared of her, and if she came again no one would talk to them. He said Zahra is the hospice's responsibility until she dies, so she will never see her family again."

Zahra, in her 60s, bears the physical deformities of chronic leprosy. Haunted eyes peer out of misshapen hollows in her face and her eyelids never close. Her hands are stretched like claws. Part of her nose is missing.

Yet far worse than the symptoms of her disease, Dr Mural said, is the stigma that comes with it.

"There's a strong belief that leprosy is a punishment from God," said Liisamaria Keates, a spokeswoman for the World Health Organisation (WHO) in Afghanistan. "People just don't believe that it comes from bacteria and it is treatable."

Leprosy, if untreated, is infectious and, because it is often passed from parent to child many rural communities believe that a whole family is being punished for a crime against Islam, Ms Keates said.

There have been at least 389 new cases of leprosy (Hansen's disease) in Afghanistan since 2001, but officials fear that the real figure is

Shunned through history

- During the Middle Ages leprosy sufferers in Europe had to wear special clothing, ring bells to warn others and walk on a particular side of the road depending on the wind direction

- In 1865 Hawaii criminalised the disease through the Act to Prevent the Spread of Leprosy. Sufferers were sentenced to permanent exile

- Romania is home to the last leprosy colony in Europe, but residents have been free to leave since 1991. Many spent most of their lives in the colony and married and started families there, so chose to stay

Sources:
www.stanford.edu/dsq-sds.org; kenyon.edu/leprosyhistory.org



higher. Many cases are unreported due to the shame attached to diagnosis and a shortage of healthcare workers.

Yet with the right drugs and the right doctors diagnosis and treatment is easy, according to WHO. Most patients are cured in 6-12 months, the drugs are free and, with early diagnosis, they suffer no permanent disabilities.

Zahra and Fatima — the only other patient at the hospice in Bamyan province — are victims of ignorance more than illness. Both are cured but because of the deformities caused before treatment started they must bear their pariah status forever.

"People are scared of us. No one visits us. Even in the hospitals when

we go there, the doctors are scared of us," Fatima said.

There are 12 leprosy clinics in Afghanistan and the WHO is working with the Ministry of Public Health to raise awareness. Leprosy cases are often misdiagnosed as leishmaniasis — a parasitic skin disease endemic in Afghanistan — because early symptoms include skin lesions, Elena Vuolo, a technical officer at WHO said. By the time that cases are identified properly, the patients have often developed disabilities.

"The real problem is late diagnosis," Dr Mural said. "People are scared of the disease, and families hide leprosy patients."

"When we find a patient with leprosy, who does not have deformations, we don't tell anyone it's leprosy until treatment is finished."

The Times first met Zahra and Fatima in October 2010 in a hospice run by a Scandinavian charity. They were in a walled compound with a small orchard at the foot of a spectacular red-rock gorge, near Yakawlang.

Zahra said that she had been living there for 16 years and Fatima had been there for 12. The Taliban shot a male patient and burnt part of the house when they were in power, but otherwise life in the hospice was peaceful. Dr Mural shook their hands and hugged them when we arrived and encouraged me to follow suit. "It's important to show people it's OK," he said.

The room filled with laughter. They joked about remarrying and we sat together drinking tea.

Ten months later, when I returned, even more tragedy had blighted their lives. They said that Ahmad Babrak, one of their carers, had doused himself in petrol and set himself alight in the garden. Neither of them knew why.

And no one had visited them since we had said goodbye last autumn, they said.