The changing face of leprosy in Timor-Leste

Patricio da Conceicao, a former leprosy patient has a wide grin on his face. He is explaining about his past experiences of stigma and how his fortunes have since changed. Rejected by his first love’s family, and excluded by neighbours, who refused to sit and eat with him, Patricio overcame the many challenges brought about by his illness. Patricio is now part of the “Noeninen Self-Care Group” in Oecusse. The group has eight members, all of whom are recovered leprosy patients. They set up a savings scheme in 2012, collecting a total of 300 dollars so far. The money can be loaned to the group’s family members should someone get sick and need to travel to the hospital, or if a child’s school fees need to be paid. With this elevated status in the community, the very people who discriminated against Patricio now want to join his group. Patricio laughs when he recalls telling the others that they need to have leprosy first if they want to benefit from his savings scheme!

Patricio is one of the fortunate ones, who was diagnosed and treated for leprosy due to the interventions and outreach activities of the Leprosy Mission Timor-Leste and the Ministry of Health. WHO has been working closely with both of these partners since 2003 to establish the country’s first National Leprosy Elimination Programme. WHO has supported the Government to developing strategic plans, policies and guidelines to combat this disease in accordance with the highest international standards.

Since 1995, WHO and partners have been providing free multi drug therapy to all leprosy patients worldwide. This had made a significant impact on the availability and accessibility of treatment in Timor-Leste. However, problems arise when patients live in remote areas and do not present to the health centre when they experience symptoms. WHO have also been providing technical assistance to the Ministry of Health through trainings and capacity building of health staff in early case detection, management and treatment of leprosy. A significant milestone was reached in 2010 when leprosy was declared eliminated as a public health problem in Timor-Leste, due to the efforts and close collaboration of the National Leprosy Elimination Programme, Ministry of Health, the Leprosy Mission Timor-Leste and WHO. The elimination of the disease means that there is less than one leprosy case for every 10,000
members of the population. However, leprosy remains a problem in the community, particularly in districts Oecusse, Dili and Baucau. With increased leprosy surveillance, the number of cases continues to rise each year. The latest figures show that 92 leprosy patients were accessing treatment at the end of September 2013, with almost half of these cases found in Oecusse. “We cannot ignore leprosy because it is already eliminated. Leprosy needs to be a high priority. We need political commitment to work with those who are already affected and transform their lives into better lives,” informed Afliana Lisnahan, manager of the Leprosy Mission Timor-Leste.

The Noeninen Self-Care Group is one of 6 that were set up in Oecusse district with the help of the Leprosy Mission Timor-Leste. Following the self-care training provided, the group comes together each day to wash themselves and put ointment on the patches of their skin affected by leprosy. Self-care groups can later be transformed into self-help groups and begin income generating activities as part of the Leprosy Mission’s “Community Based Rehabilitation” (CBR) Programme. Mostly groups want to grow vegetables to sell in the local markets, so the Leprosy Mission will provide the members with skills in micro-financing and book keeping and provide a small loan. The group then decides how much money they will repay each month. The CBR Programme’s core focus is to strengthen the resilience of the group member’s livelihoods, prospects and future.

To highlight the importance of tackling leprosy, the Vice Minister of Health, H.E. Sra. Natalia de Araujo and senior representatives from Ministry of Health, The Leprosy Mission and WHO, travelled to Oecusse for the celebration of World Leprosy Day on January 31st 2014. The Vice Minister met with Patricio and the Noeninen Self-Care Group in their homes to listen to their experiences of leprosy and understand the challenges faced by communities in hard to reach areas. H. E. Sra. Natalia informed the group of the government’s work on leprosy, training health workers and over 500 community health volunteers to refer suspected cases for diagnosis and treatment. H.E. Sra. Natalia then made a donation on behalf of the Ministry of Health to the group’s savings scheme and stressed the importance of early access to diagnosis and treatment for any future health complaints.

Awareness of leprosy has greatly increased in rural communities thanks to the advocacy efforts of the Ministry of Health and the Leprosy Mission. However, poverty, poor housing conditions and sanitation are drivers of the disease and until these conditions improve for people in the districts, leprosy will continue to pose a challenge to the national and district health services. In the meantime, stories like those of Patricio give hope and inspiration to others affected by leprosy. Patricio married his wife Justina, after overcoming the initial opposition of her family. They now have four healthy children. He assured the family that leprosy cannot be transmitted once treatment is completed and that he is fully cured. With a glint in his eye, Patricio beams “love will conquer all!”