

When Culture Impacts Health

Global Lessons for Effective Health Research

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Perceptions of Leprosy in the Orang Asli (Indigenous Minority) of Peninsular Malaysia

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INTRODUCTION

Orang Asli (“original man”) is the generic name for eighteen distinct ethnic groups that collectively make up the indigenous minority of Peninsular Malaysia. While the term indigenous is both complex and highly contested and no universally agreed definition exists, the Orang Asli fulfill the key criteria to be regarded as indigenous according to the United Nations Working Group on Indigenous Populations (Kenrick, 2004; United Nations, 2007). Their minority status is undisputed. Numerically they make up a tiny proportion (0.58%) of the Peninsula’s population (JHEOA, 2004). In 1991, their literacy rate was 30% compared with the national rate of 86%; in 2004, 76.5% of Orang Asli lived below the poverty line compared with 6.5% of other Malaysians; 45.7% of Orang Asli villages were classified by the government as underdeveloped; and 41.7% were located in interior regions of the country (Baer, 1999; Nicholas, 2000; JHEO, 2004; Nicholas and Baer, 2007).

There is widespread international recognition that indigenous peoples across the world have substantially lower than average standards of health for the nation state in which they reside (Stephens et al., 2006). Indigenous peoples have disproportionately high levels of communicable and vector-borne diseases and high levels of cancer, respiratory disease, stroke, and diabetes. They show increased morbidity and mortality levels compared to other population groups, a substantially lower life expectancy, and elevated infant and child mortality rates (Stephens et al., 2005).

Research into the standards of Orang Asli health in comparison to other Malaysians echoes this pattern. In 2004, the Orang Asli average life expectancy at birth was 53 years compared with the national average of 71.5 years, and their average infant mortality rate was 51.7 deaths per 1,000 births compared to

the national average of 16.3 deaths per 1,000 births (JHEOA, 2004). The Orang Asli suffer from high incidence rates of tuberculosis and malaria; malnutrition is common; and levels of diabetes, hypertension, and cancer are increasing.

The incidence of leprosy in Orang Asli is also highly elevated compared to the national level and, according to the World Health Organization (2003), Malaysia eliminated the disease in 1994. In 2005 (the most recent complete data available), the Ministry of Health recorded the incidence rate in Peninsular Malaysia at 0.07 per 10,000, and for the Orang Asli, an incidence rate of 1.34 per 10,000. Only one previous publication deals with leprosy in this community (Kamaludin, 1997), and it reviews a 1994 survey of various groups, but provides scant data. Other works addressing Orang Asli health cite cases of leprosy only in passing. The research on which this chapter is based is the first anthropological study focusing on leprosy in the Orang Asli.¹

The Department of Aborigines, now known as the Department for Orang Asli Development (*Jabatan Kemajuan Orang Asli Malaysia*; JAKOA, and before January 2011 as the Department of Orang Asli Affairs, *Jabatan Hal Ehwal Orang Asli*; JHEOA) has, since its formation in 1950, assumed responsibility for the “administration” of the Orang Asli with a mandate to assimilate the minority into mainstream Malaysia (JHEOA, 1961). Its medical division was established in 1953 as part of the “hearts and minds” campaign in which welfare measures were offered as an incentive for the community to side with the British administration against the communist insurgency during the Emergency period (1948–1960; Bedford, 2009).

This medical division remains the government’s only health service provider that is organized according to ethnic criteria, and it is run with relative autonomy by the JAKOA, not the national Ministry of Health. The Orang Asli are, therefore, the only community in Malaysia to receive a discrete state-run medical service. The hub of the JAKOA medical division is Gombak Hospital, also known as the Orang Asli hospital, located on the outskirts of a northern suburb of Malaysia’s capital, Kuala Lumpur. Orang Asli are permitted to receive free health care at any government clinic or hospital in the country, yet many travel long distances to seek treatment at Gombak as they regard it as “their” hospital. Patients report feeling less vulnerable seeking biomedical treatment at Gombak where they perceive risks associated with non-Orang Asli interaction to be reduced. Due to its orientation and location, however, the hospital is widely considered to be an isolated backwater of the medical profession in Malaysia. It is under-resourced in terms of funding, facilities, and staff, and the standard of health care offered often falls below that practiced in mainstream government hospitals.

1. The term Hansen’s disease is favored in some recent literature. I use the term leprosy in line with the International Federation of Anti-Leprosy Associations and the World Health Organization. The term “leper” is, however, widely condemned as pejorative and stigmatizing and is now largely redundant. I use the phrase “leprosy patient” in reflection of the patients’ self-identification.

Drawing on data gathered as part of a larger research project based at Gombak Hospital, which explored relations between the Orang Asli and the nation state through the lens of biomedical health care provision (Bedford, 2008), this chapter investigates the occurrence, treatment, and social presentation of leprosy in the Orang Asli, and discusses how, in light of their status as the indigenous minority of Peninsular Malaysia, leprosy assumes additional social configurations beyond its clinical manifestations.

METHODS

Data Collection

Research was conducted over a 9-month period (2004–2005) at Gombak Hospital and with the JAKOA medical division's mobile health teams and flying doctor service, visiting communities and rural clinics in the isolated interior of the country. Quantitative data were collated from JAKOA, the Ministry of Health, and from patient records at Gombak Hospital. Core empirical data were qualitative and gathered through a combination of methodological tools including in-depth interviews with key interlocutors (patients, community members, and health care professionals), focus group discussions, case studies and narratives, and direct and participatory observation. Open inductive qualitative methods ensured that multiple perspectives were considered and the quality of data gathered was maximized through triangulation. Participant observation was fundamental to the research, as it allowed insight into inconsistencies between actual and reported relations between Orang Asli patients and non-Orang Asli staff, which was a highly sensitive and political issue.

Detailed case studies were compiled of all leprosy patients admitted to Gombak Hospital during the research period ($n = 32$). A case study consisted of at least one in-depth interview with the patient, an interview with the patient's accompanying relative if possible, a detailed medical case history, documented treatment regime, and at least one briefing from the doctor managing the case.

For the in-depth interviews, a broad spectrum of research questions was designed and used as a semi-structured topic guide. Specific questions and probes were reviewed and refined during the research period in light of themes arising. The direction and content of each interview were determined by the key interlocutor and largely focused on issues they self-prioritized.

Interviews with patients and their accompanying relatives were conducted at Gombak Hospital, most often on the communicable disease ward, and were held in as much privacy as possible. At the start of each interview, it was made clear to the interlocutors that their participation was optional and voluntary, and would not affect any future referral or medical service required or received. Each interview lasted for approximately one hour. Audio recordings were not made. This helped foster a sense of trust and privacy and encouraged patients to speak more candidly than may otherwise have been possible.

Data Analysis

Preliminary analysis was conducted in-country throughout the research process. Detailed notes were compiled during every interview, and at the conclusion of each day were transcribed and annotated with initial comments. The interviews were conducted in Malay and translated into English. Sections of narratives were transcribed *ad verbatim*, translated, and back-translated and statements checked with the interviewee. All data, interview notes, and completed case studies were regularly reviewed.

The case studies were thematically analyzed at the end of the fieldwork period. Dominant themes were identified through the systematic sorting of data, labeling ideas, and phenomena as they appeared and reappeared. The emerging trends were critically analyzed according to the research objectives. Coding and analysis were iterative and by hand. A qualitative software package was not used.

Preliminary findings were discussed with the JAKOA medical division and other key stakeholders including the Selangor Public Health Department and the national Tuberculosis and Leprosy Control Unit of the Disease Control Division of the Ministry of Health. Their feedback was appropriately incorporated into the final analysis.

Ethical Considerations

The study was conducted in line with prevailing ethical guidelines to protect the rights and welfare of all participants. All data were kept confidential and anonymous. Overall permission for the research was granted by the Economic Planning Unit of the Prime Minister's Office in Malaysia. As no biomedical interventions were undertaken during the research, formal ethical consent was not required by Gombak Hospital or the JAKOA. Every effort was taken, however, to ensure that all those who participated in the research were given detailed information about its objectives and methods prior to their voluntary involvement. All participants gave their assent and were given the opportunity to seek clarification or ask questions at any time during the research.

CASE STUDIES

Due to space constraints, it was not possible to present the full qualitative analysis of the 32 case studies completed. Rather, the following excerpts from three longer case studies can be considered representative and illustrate the dominant themes of stigma, compliance, and responsibility discussed in the following sections.

Case Study 1—Itah

Itah had advanced lepromatous leprosy. He was 46 years old and had been first diagnosed in 1996. He had periodic treatment for one year due, he claimed, to

an infrequent supply of medication. He had extensive anesthesia accompanied by anhidrosis and marked thickening of his facial skin. His anterior nasal spine had been destroyed resulting in a collapsed nose. His hands and feet were edematous with marked shortening and angulation of the digits on both hands. Itah had a quiet confidence and a large smile. His narrative was given on the ward in Gombak Hospital, sitting on the floor next to his bed as he flicked through the day's newspaper.

I have had leprosy for nine years. It began with pale patches. I had those for four years and then I started to lose the feeling. I think I was infected by my friend. There were three men in my village with the same illness. The other two have already passed away. My friend came to Gombak for treatment, but he came back to the village without finishing the medicine.

Before I came here, I went to a private clinic. They gave me injections for my illness. I have never been to Gombak for treatment before this year. The JOA [JAKOA] medical staff brought me to the hospital. I came with my family, but now they have all gone back to the village. It is better that they are in the village, then they can work.

At first I did not know what the patches were because they were bigger than normal [fungal] skin infections. But eventually I knew it was leprosy. I wanted to come to Gombak before to have treatment. But when the health teams went to the village, I was in the jungle working. I could not come by myself, I don't have transport. So it was very difficult. I was frightened, of course, this is normal. I could not come before. But now I do not have fingers, toes or my nose. There was no way I could come by myself. I do not feel angry. It is just one of those things, so I am sad. This [looks at his hands] only happened recently, about three years ago. I lost all sensation in my hands and feet. I had no feeling at all. But now with treatment, the feeling is coming back. Its ok, its not getting worse.

I miss my wife and children. I want to go home at the end of this month and take the medicine with me. I understand that I must keep taking it. I am worried my children will get this illness. But they have all been screened and are healthy. People in my village were worried when I became ill. They were worried they might get ill too. This is one reason I came for treatment.

Case Study 2—Tengah

Tengah was 36 years old when he came to Gombak with advanced lepromatous leprosy that had progressed untreated for 15 years. When he arrived in hospital transport, accompanied by his mother, he had severe malnutrition and a very low hemoglobin count. He was transferred to the central hospital in Kuala Lumpur for blood transfusions before starting multidrug therapy at Gombak for his leprosy. He was an inpatient at the hospital for 8 months.

Before he was brought to Gombak, the medical division had been aware of Tengah's deteriorating condition for many years. Whenever a mobile team visited his village, Tengah would hide in the surrounding jungle fringe, sometimes for days, until they had gone. Retreat or withdrawal from medical intervention, rather than confrontation, was a common tactic. Tengah's immediate community

supported him and his family, and by so doing indirectly protected him from receiving treatment against his will. He eventually allowed himself to be brought to the hospital when his condition became too grave for his family to provide adequate care. Only then did he consider himself to be ill. When asked if he would have come for treatment when he first contracted leprosy had he known it would have arrested his condition, he smiled shyly and replied “probably not.”

Case Study 3—Ana

Ana was diagnosed with lepromatous leprosy when she presented at the hospital in 2004 with widespread intense itchiness followed by the development of anesthetic patches on her face. After one month as inpatient, she absconded. Her husband perceived the treatment lacked efficacy as her symptoms were not markedly reduced. Over the following months, the medical division’s mobile health teams tried to persuade her to return to the hospital and sent medication to her in the village.

Simultaneously, Ana’s husband arranged for her to see a *bomoh* (traditional healer), believing the *bomoh* could more effectively treat his wife. When her condition continued to deteriorate despite the *bomoh*’s interventions, the mobile team succeeded in persuading Ana to return with them to Gombak. In the interim, she had developed classic leonine features with pronounced thickening of the ear lobes, malar surfaces, and marked hair loss.

Four days after her readmission, her husband arrived at the hospital and insisted on taking Ana back to their village. He would not condone Ana’s condition being treated in any way other than by his local *bomoh*. He sought to minimize interaction with the hospital and assiduously avoided the medical division and JAKOA authorities.

DISCUSSION

In Malaysia, the propagation of biomedicine is a sign of modernity legitimized by the rationale of the scientific. Biomedical health care is part of a comprehensive strategy of social transformation (Chee and Barracolough, 2007). In direct and meaningful ways, health care provision engages a specific discourse about states of modernity and progression versus states of underdevelopment and backwardness. Ethnicity remains the dominant ideological framework of contemporary Malaysia, and stereotypes are played out at Gombak hospital along ethnic lines of Orang Asli versus the nation state. In its very existence, Gombak perpetuates this discourse: it is the hub of a medical service for the indigenous minority and is distinct from mainstream health care. This dichotomy also influences the interpretation of disease and illness. Leprosy both represents and accentuates the divide: it has been characterized by some as a disease of the unclean, deviant, backward, or underdeveloped (Vaughan, 1991), and while it has been eliminated nationally, its incidence remains elevated among the Orang Asli.

High levels of stigma associated with leprosy are well documented, yet it is not universally stigmatized, and there have been recent calls for a more nuanced and less constrained interpretation of stigma and social exclusion in relation to the condition (Staples, 2011). There was no evidence to suggest that Orang Asli leprosy patients at Gombak Hospital had been stigmatized by or excluded from their village or community. Rather, patients described scenarios in which they remained fully integrated in their community. In the second case study, Tengah and his immediate family were supported both socially and financially by their community for a number of years. In the third case study, Ana was repeatedly taken back to the village by her husband who was distressed by admission to the hospital and preferred her to remain within the immediate confines of their community.

At Gombak Hospital there was no detectable change in behavior or attitude within the patient body toward a fellow inpatient with leprosy. Non-leprosy patients attached no particular significance to the condition, and interacted freely with the leprosy patients. The stigma that was evident came from the medical staff. For example, dental clinicians routinely refused to treat leprosy inpatients and other health care professionals sought to avoid work on the communicable disease ward. Studies have shown that doctors often display the highest levels of stigma toward individuals with leprosy, despite leprosy being one of the least contagious of human transmissible diseases (Scott, 2000; Arole et al., 2002). In light of this discrimination, Pfaltzgraff (2003) suggested that the problem of stigmatization should be considered from the perspective of the stigmatizer rather than the stigmatized.

Medical staff at Gombak stigmatized patients like Itah, Tengah, and Ana and labeled them noncompliant or uncooperative given their late presentation and history of defaulting treatment. As his narrative highlights in the first case study, Itah had been prevented from seeking sustained treatment by insurmountable logistical barriers involving transport and work patterns. Although he complied with the treatment regime while at Gombak, his late presentation and the fact that he had undergone inappropriate treatment earlier in his illness (injections at a private clinic) ensured that, in the eyes of the medical staff, his case history did not follow the preferred model of early detection, effective diagnosis, and successful treatment. His illness had progressed under the pressure of socioeconomic realities, where self-care took second place to daily survival. The discourse of compliance [Donovan and Blake, 1992; Donahue and McGuire, 1995; Ogden, 1999] broadly assumes that all patients are equally able to comply in the first instance, whereas in practice, as Farmer (1997) showed, “throughout the world, those least likely to comply are those least able to comply.”

It was inconceivable to many medical staff at Gombak that Tengah had not sought treatment for his deteriorating condition. To them, his avoidance was irresponsible, even deviant. Within his framework of reference, however, his (non-)actions have a logical consistency. During the years prior to his admission, Tengah did not perceive himself to be ill, nor in need of treatment, because

he was able to continue contributing to the social and economic life of his community. His case highlights the contest for medical knowledge: When is a person ill? When should they receive treatment? What treatment should they receive? Who should assume responsibility for it? What is the relationship between the clinical reality of a biomedical framework and the social reality of illness (of leprosy) as experienced by an Orang Asli patient?

Staples (2007) argued that for many leprosy patients, the medical cure of their illness that meant they were no longer infectious is socially irrelevant as many are “permanently rendered ‘lepers’ by what their corporeal appearance had come to signify.” This was true of Tengah, whose severe physical impairments were, for the medical staff, a constant and magnifying reminder of his nonconformity and their lack of control. For Ana, the absence of immediate improvement with treatment at the hospital influenced the treatment-seeking behavior sanctioned by her husband. His dissatisfaction with treatment exacerbated his reluctance for her to be admitted to the hospital rather than remain in their own village. He did not want to deny treatment for his wife per se, but wanted to avoid biomedical treatment, preferring instead to engage the “traditional” health care of the *bomoh*. Undergoing treatment at Gombak Hospital necessitated crossing into a non-Orang Asli dominated environment that he understood in terms of the prevailing dichotomy of indigenous Orang Asli versus mainstream Malaysia. To him, Gombak and biomedical treatment represented diminished autonomy, generalized stigma, and the inherent threat of assimilation.

During my research, I was asked this by a Malay nurse:

Why are you interested in leprosy? Leprosy is an old disease. That is why the Orang Asli have it. They don't have new modern diseases like HIV and AIDS. There is no leprosy anywhere in Malaysia now, except in Orang Asli. Leprosy is appropriate for them.

It is explicit that the nurse's perception of leprosy as an old disease made it appropriate for the Orang Asli, in contrast to conditions that she associated with modernity and progression typified by HIV/AIDS. In India, Staples (2004) found that leprosy and leprosy patients were often regarded as “obstacles to development.” Similarly, the Orang Asli are generally characterized within Malaysia as impediments to modernization. According to Nicholas (2000), “the state perceives that it cannot modernise effectively if it were to tolerate indigenous minority culture in its midst.” Despite such opinions being common among medical staff, the notion of being doubly marginalized, of being in “double jeopardy” due to being Orang Asli and having leprosy, was widely denied by patients at Gombak Hospital (Morrison, 2000). To them, any additional stigma concerning their leprosy was normalized by its interpretation as typical anti-Orang Asli sentiment. As Waitzkin (1984) concluded, “the medical encounter is one arena where the dominant ideologies of a society are reinforced.”

CONCLUSION

In the context of Gombak Hospital, leprosy is an illness where notions of responsibility, compliance, and stigma collide, and where experiences of health, illness, and treatment-seeking behavior are expressed along ideological and ethnic lines. In light of their status as the indigenous minority of Peninsular Malaysia, leprosy in the Orang Asli community assumes additional social configurations beyond its clinical manifestations.

Understanding these sociopolitical determinants of illness and the complexities around seeking and adhering to treatment enables us to better appreciate the context in which the delivery of health care functions. It is imperative for the effective design and implementation of health care programs that policies are properly contextualized, locally appropriate, and acceptable. It is not sufficient to have biomedical services in place and expect patients to attend and comply with treatment. Instead, we must focus on the interface between service delivery and uptake and find ways to maximize drivers that lead to positive treatment-seeking behavior while minimizing barriers that prevent it. With regards to leprosy, this would enable a move away from the problematic notion of elimination toward a more relevant and nuanced understanding of the condition and its treatment.

Reflections on Methodological Approach

One of the greatest hurdles in conducting this research was securing all necessary permissions from various branches of the Malaysian Government. Research with the Orang Asli is a highly sensitive issue in Malaysia for sociocultural, political, and religious reasons connected to issues of indigeneity and assimilation. Careful planning and substantial time were required to prepare adequately before the research could commence.

The research methodology proved effective and efficient as I was based at the hospital for an extended period of time and was able to build trusting relationships with both patients and staff through participant observation. Initially I was concerned that the patients and wider Orang Asli community would align me too closely with the JAKOA; however, I was able to establish a betwixt and between position. The patients grew to see me as a confidante and were encouraged by my overt interest in their community, while the medical staff regarded me as a health care professional working alongside them in a non-medical capacity. In both cases, I was seen as being on “their side” yet somehow different, and this afforded me considerable insight into the workings of Gombak Hospital.

A limitation of the research design was that all of the leprosy patients I worked with were inpatients at Gombak Hospital. It would have been interesting to have also included people with leprosy who remained in the community and were not in treatment. Given the constraints of time and difficulty in

identifying these potential interlocutors, particularly in the remote interior of the country, it was not possible during this research.

In qualitative research of this kind, issues of translation and interpretation can be problematic. I did an intensive course in Malay (the national language) before starting fieldwork and did not conduct interviews or record narratives until I was confident in my linguistic ability to do so accurately.

REFERENCES

- Arole, S., Premkumar, R., Arole, R., Maury, M., Saunderson, P., 2002. Social stigma: a comparative qualitative study of integrated and vertical care approaches to leprosy. *Leprosy Review* 73, 186–196.
- Baer, A., 1999. Health, disease and survival. Centre for Orang Asli Concerns, Malaysia.
- Bedford, K.J.A., 2008. Gombak and its patients: Provision of healthcare to the Orang Asli (indigenous minority) of peninsular Malaysia. Unpublished D.Phil thesis. University of Oxford.
- Bedford, K.J.A., 2009. Gombak Hospital, the orang asli hospital: government healthcare for the indigenous minority of Peninsular Malaysia. *Indonesia and the Malay World* 37, 23–44.
- Chee, H.L., Barraclough, S., 2007. Health care in Malaysia: The dynamics of provision, financing and access. Routledge, London.
- Donahue, J.M., McGuire, M.B., 1995. The political economy of responsibility in health and illness. *Social Science and Medicine* 40, 47–53.
- Donovan, J.L., Blake, D.R., 1992. Patient non-compliance: deviance of reasoned decision-making? *Social Science and Medicine* 24, 507–513.
- Farmer, P., 1997. Social scientists and the new tuberculosis. *Social Science and Medicine* 44, 347–358.
- JHEOA., 1961. Statement of policy regarding the administration of the Orang Asli of Peninsular Malaysia. JHEOA, Kuala Lumpur.
- JHEOA., 2004. Data Maklumat Asas. JHEOA, Kuala Lumpur.
- Kamaludin, F., 1997. Strategies to overcome infectious disease among the Orang Asli—leprosy and tuberculosis. Paper presented at Emerging Trends in Infection. Second National Conference on Infection and Infection Control, Ipoh, Malaysia 14–16 March 1997.
- Kenrick, J., Lewis, J., 2004. Indigenous peoples' rights and the politics of the term “indigenous.” *Anthropology Today* 20, 4–9.
- Morrison, A., 2000. A woman with leprosy is in double jeopardy. *Leprosy Review* 71, 128–143.
- Nicholas, C., 2000. The Orang Asli and the contest for resources. International Workgroup for Indigenous Affairs, Copenhagen.
- Nicholas, C., Baer, A., 2007. Health care for the Orang Asli: Consequences of paternalism and non-recognition. In: Chee, H.L., Barraclough, S. (Eds.), *Health care in Malaysia: The dynamics of provision, financing and access*, Routledge, London, pp. 119–136.
- Ogden, J.A., 1999. Compliance versus adherence: Just a matter of language? The politics and poetics of public health. In: Porter, J.D.H., Grange, J.M. (Eds.), *Tuberculosis: An interdisciplinary perspective*, Imperial College Press, London, pp. 213–234.
- Pfaltzgraff, R.E., 2003. Begging as a profession and debilitation among leprosy patients. *Leprosy Review* 74, 280–281.
- Scott, J., 2000. The psychosocial needs of leprosy patients. *Leprosy Review* 71, 468–491.
- Staples, J., 2004. Delineating disease: self-management of leprosy identities in south India. *Medical Anthropology* 23, 69–88.

- Staples, J., 2007. Peculiar people, amazing lives: Leprosy, social exclusion and community making in south India. Orient and Longman, Delhi.
- Staples, J., 2011. Interrogating leprosy stigma: why qualitative insights are vital. *Leprosy Review* 82, 91–97.
- Stephens, C., Nettleton, C., Porter, J., Willis, R., Clark, S., 2005. Indigenous peoples' health—why are they behind everyone, everywhere? *Lancet* 366, 10–13.
- Stephens, C., Porter, J., Nettleton, C., Willis, R., 2006. Disappearing displaced and undervalued: a call to action of indigenous health worldwide. *Lancet* 367, 2019–2028.
- United Nations, 2007. Declaration on the Rights of Indigenous Peoples <http://daccess-dds-ny.un.org/doc/UNDOC/GEN/N06/512/07/PDF/N0651207.pdf?OpenElement>.
- Vaughan, M., 1991. *Curing their ills: Colonial power and African illness*. Polity Press, Cambridge.
- Waitzkin, H., 1984. The micropolitics of medicine: a contextual analysis. *International Journal of Health Services* 14, 339–378.
- World Health Organization, 2003. Overview and epidemiological review of leprosy in the WHO western and pacific region 1991–2001. World Health Organisation Regional Office of the Western Pacific, Manila.