WORKSHOP REPORT

The prevention of leprosy related disability as an integral component of the government health delivery programme in Myanmar

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Summary  This paper presents a record of a focus group discussion that took place in Nyapyitaw, Myanmar in December 2010. Those contributing to the focus group discussion were senior post holders in the National Leprosy Control Programme (NLCP), Myanmar. The Myanmar programme had been targeted for further enquiry after it became apparent, through an earlier survey of national programme managers and consultants, that the programme had been relatively successful in the measures taken to facilitate the integration of POD into the government health delivery programme. The experience gained by the NLCP, Myanmar was recorded and is offered here as an example of how POD can be successfully developed by a government leprosy control programme to become integral to general health delivery.

Introduction

In 2009 a survey of leprosy programme managers and consultants was undertaken, salient findings from which were published in 2010. One of the objectives of the survey was to ascertain which national programmes had managed to implement or influence the implementation of robust prevention of disability (in some countries leprosy prevention of disability is an integral component of other health programmes). Under the terms of the survey, programmes were deemed to be well placed for the provision of prevention of disability (POD) if the following essential criteria were reported:

- There is a person, or group, with specific responsibility for POD, who facilitates improvement of POD coverage through a Government program in the country.
- There is a specific action plan for POD that has been developed/implemented through a Government program.
An assessment of the extent of leprosy related disability (focal or national) or specific plans to conduct an assessment of extent of leprosy related disability (focal or national) has been undertaken.

There are specific plans for POD related operational research in the country supported by the national programme.

In an attempt to ensure consistency there were a number of questions relating to each criterion, answers to which gave clearer definition to each of them. None of the 23 programmes considered fully satisfied all the criteria but the Union of Myanmar, National Leprosy Control Programme (NLCP) was one of four national programmes that reported programme characteristics that satisfied most of the essential criteria. The principal shortfall in the Myanmar Programme was that although some areas defined as “highly endemic” had been assessed there had not been a nationwide assessment of disability. Highly endemic areas had been targeted for POD development by the NLCP with support from the Netherlands Leprosy Relief (NLR) and the American Leprosy Missions (ALM) jointly and by Japan International Cooperation Agency (JICA). Disability surveys had been undertaken to establish baseline leprosy related disability statistics. Another issue was that there were no specific plans to conduct POD related operational research. Health systems research, however, is integral to the NLCP and POD related topics are routinely investigated.

Systematic evaluations of the NLCP and the POD component thereof have been conducted since 2002 by NLR and ALM jointly and by JICA (for further detail, please see the discussion section of this paper).

An understanding of the structure of the Union of Myanmar’s Health Care Services and the interaction between the Specialist Leprosy Services and the General Health Services is necessary: for this purpose a diagrammatic representation of these structures is presented in Appendix 1.

Method

UNION OF MYANMAR POD PROGRAMME: FOCUS GROUP INTERVIEW

On the 12th of December 2010, at the NLCP Headquarters, Naypyitaw, the author held a focus group interview with a group of senior post holders in the NLCP, all of whom had significant involvement with POD. The objective of the interview was to record lessons from their experience that might prove to be informative for other national programmes. The names of the contributors to the focus group interview are disclosed an Appendix 2.

Prior permission to conduct and record the interview had been obtained through the office of Dr Tin Shwe (ILEP Representative, Myanmar) who also assisted with the logistics of the project. The interview was recorded on a voice recorder. The voice recording was transcribed at a later date.

Following introductions and an explanation of the reason for the interview the author (HC) presented the group with questions. The questions and responses are presented verbatim allowing for some minor grammatical adjustments.

Results

HC: – How did POD come to be viewed as important in the Myanmar NLCP?

‘Ever since the leprosy control programme started in 1952 we set survey, education and treatment as the main programme functions. In 1970, as part of the education
component, we started to include patient education on self-care and we took care from then that training of our junior leprosy workers had an emphasis on the training of PWD (people with disabilities).

HC – Please confirm: in 1970 self-care training became the responsibility of the junior leprosy workers?

‘Yes – and then, as we were progressing towards elimination in 2002, we had a discussion with NLR and a Health Systems Research (HSR) on POD in Myanmar was suggested. Then, after achieving the elimination goal in 2003 we held a HSR workshop for the planning of POD with an NLR consultant in Yangon. Following that, we started to implement the POD pilot project in Shwedaung and Thegone, two townships of Bago division. After two years of implementation an evaluation team visited and it was found that the programme was benefiting the patients at the periphery through the integrated approach using the BHS (Basic Health Staff) midwives. It was the midwives who took responsibility for giving self-care education and for monitoring progress.

So, after two years experience of the programme working well in Thegone and Shwedaung it was decided that we should expand the programme to more townships. We thought that it would be good to expand to all the townships in Bago Division so we included all the 26 townships in Bago Division – that started in 2006. After the pilot project was evaluated and there was a renewal of the tripartite agreement (NLR, ALM and MNLCP) it was then planned to increase to 70 townships each year until complete coverage was achieved. Now a total of 117 townships have been included.

At the time of conducting the HSR, JICA came in to support the Myanmar Leprosy Control Programme and they were also interested in the POD activities so they started to duplicate the activities in their designated areas as well.

In all the targeted townships we integrated POD with the BHS (Basic Health Services) and POD activities were implemented through the midwives. The midwives were very committed and we were very happy with the way they conducted the necessary activities.

What I feel was important for the success of the programme is, first of all, the commitment of the midwives and other BHS staff.’

HC – How did you get that commitment?

‘Through advocacy, explaining to them that this (leprosy disability) is a national problem. We said to them that the delivery of POD to our leprosy patients is a problem for our national leprosy control programme.’

HC – Please confirm: you considered the patriotism of that cadre of health workers and encouraged them to adopt the attitude that by conducting the required activities they would be helping the country?

‘Yes, but we also explained that these people affected by leprosy are our neighbours and you (midwives) stay in the villages where these people live too. We are duty bound to
look after their needs. They then took the challenge very seriously and stayed committed to it. The commitment of the BHS is the top most force that made this programme effective.

The second most important factor is the commitment of the specialised leprosy services (SLS). They conducted training of the BHS and followed that up with supervision which included repeated OJT (on the job training). They also maintained very good records of the progress of every patient individually.

The third factor is the political commitment from the highest levels in the government, starting at the ministry of health. Once we had declared that we had attained elimination the minister himself said that we must focus on POD and rehabilitation.’

HC – How did you manage to get that political commitment to POD in Myanmar?

‘It was through advocacy and personal contact. A former director of the NLCP took steps to ensure that the NLCP had ready access to the minister and through that link we advocated that POD should be an important component of leprosy control.’

HC – Please confirm: it was the commitment of successive leprosy control directors who were able to advocate successfully to the minister. If so, how much does that depend on personality, or is it that a person in a certain role has entitlement to access a minister?

‘It was not so much due to personal contact. We were able to persuade the minister that POD was an issue. He was convinced by our persuasion. Personal relationship did mean that we could talk more openly than if he had been somebody else, but he became fully convinced that POD was important and that commitment came down the line to the staff.’

‘Another important factor was the support from ILEP members for logistic supplies. This played an important role in the success of the programme, because whatever supplies the leprosy teams needed: footwear, glasses or even splints, they found that these were supplied by the ILEP members through the tripartite agreement. This encouraged the periphery workers because they knew that they could supply essential aids to the patients.’

HC – From your personal perspectives, what do you feel have been the most important factors that have contributed to the success of the programme?

‘I was promoted in the programme (now based in Naypyitaw) but previously I was very close to BHS and specialised leprosy staff in Pyay Division. It was not just the leprosy programme but also malaria and TB that were integrated and the BHS staff knew that these were their responsibilities. But there was a closer relationship between the specialised leprosy services and the BHS than there was between other programme staff and the BHS. After the elimination era, when we were focussing more on POD activities, they (BHS staff) were ready to accept these (POD) responsibilities. One thing was very difficult: as you know we conducted training for 3 days and then drew up plans for each township with follow up assessment after 6 months. During baseline activities we found
the cases to be very high and some lived in very far and difficult to reach places this was very difficult for the BHS workers when they undertook the survey and for follow up. But even still they did most of it very well.’

HC – What motivated them to do it so well? It was said earlier that they do it out of a sense of national pride, do you have any other explanation?

‘Our Myanmar BHS workers really want to fulfil their duties and if they are working with the leprosy specialised staff they are willing to do what is required.’

HC – Are they as dedicated to other programmes, for example, malaria, do the BHS workers have the same level of dedication, or is there something special about leprosy?

‘I’m not sure, but before elimination they worked very closely with the specialised staff and then after elimination they all continued together. The close working relationship between the BHS and the specialist leprosy staff is very important.’

HC – An interesting feature in Myanmar is that although you don’t have a vertical leprosy programme you have still got specialised leprosy service (SLS) teams. Do you feel that these have been important?

‘Yes, but they must be able to communicate well with the BHS workers. In some areas they have not been communicating so well and there it has not been as successful.’

HC – Do other disease control programmes in Myanmar also have specialised teams in the same way that the leprosy programme has? For example, does the filariasis programme have specialist staff?

‘They do have for malaria and TB at township level, but not for other programmes. But they don’t seem to be as effective as the specialist leprosy teams.’

HC – Was anybody from this group involved in the HSR that was mentioned earlier?

‘Nobody here was involved in that first HSR in Shwedaung and Thegone but subsequently there was another HSR workshop which Dr Soe Thet and Dr Win Maw attended.’

HC – What was learned from that?

Dr Soe Thet: ‘I analysed changes in impairment status at the time of registration and after RFT for nearly three years. I found that reaction episodes were associated with changes in impairment status and that it was really important for BHS to know about reactions so that patients could be treated as early as possible, but also that patients and their families should be aware of the risk of reaction so they can get early referral to the health centre. Our junior leprosy workers have responsibility for directly observed treatment but they are also now responsible for giving knowledge and information to the patients when they come to the health centre. So compliance is very high.’

Dr Win Maw: ‘I analysed factors associated with changes in disability between diagnosis and RFT. In our study we found that MB cases showed more changes in
disability status than PB. We also found that disability at RFT was related to the extent of nerve damage at diagnosis (increased disability was related to multiple nerve involvement). We also found that changes in disability were also dependent on patient compliance.'

HC – In Myanmar there is very detailed recording. Specialist Leprosy Service workers are using impairment summary forms, what recording responsibilities do the BHS workers have?

'They don’t do that level of recording, only the specialist staff record that impairment data, but they do conduct VMT and ST and they record that in patient files.'

HC – Do you find that the midwives complain about having to do that work?

'Not at all. I remember there was one lady in Inna who complained because she had too many people to cover. She was from a semi urban area and she had about 35 clients to look after so she said that was too much for her, but in many places the midwives have less than 10 leprosy affected clients and this number they don’t complain about.'

HC – The importance of ILEP for the provision of logistic supplies was stated earlier, but are there other features of ILEP partnership have been important?

'With ILEP support we sent four medical officers to Pokhara for state of the art POD training. To strengthen headquarter and division level we also sent two people to KIT (Koninklijk Instituut voor de Tropen) to undertake MPH studies. Some of our leprosy inspectors were also sent to other countries like Indonesia and Viet Nam to see the POD activities that were being implemented there. We sent four people at a time to study those activities. They gained good knowledge but these were also motivating factors for the staff. ILEP Funds also enable the training of BHS and specialised leprosy staff for POD. It was not only the knowledge they gained, but just being sent for training was a motivating factor for them. ILEP provision also enhanced the supervision of activities in the townships.'

HC – Without ILEP support, how would this programme have proceeded?

'ILEP support has been very valuable, but POD is so important and brings such benefit to the clients that even if ILEP did not support it we would find some way of continuing it. It is very important to our clients.'

HC – Please confirm: even if you did not have ILEP support you could still have done the essential work needed?

'Without ILEP support we would not have done it so fine, but I think we would still have done the work. We will not have had as good results, but we would have done what we could. ILEP support has definitely been very important to our programme.'

'This question was first asked to me in April 1995 Dr Yuasa and Dr Noordeen said to us, “we see this programme as a good programme if we are not going to support it what will you do?” They were told: “we take this programme as our national programme and it is
our duty to tackle it, if support comes from partners we can accelerate it and do it better. If there is no support we will do the work, but it will be slower and the achievement will be less." The same answer applies today.'

HC – How important has it been to the programme to have medical officers study for MPH and to have people undertake HSR training?

'It helps particularly with planning and also for analysis of problems.'

HC – Have the findings of the various HSR projects been used to bring about changes in the programme and if so what is the process by which new knowledge is used?

'The operational guidelines were influenced by my research findings; they resulted in the standardisation of various methods. We found that it was necessary to involve the patient and family members so, for example we standardised what should be done for claw hands so that everybody could learn and apply it. Formerly we had so many procedures but we reduced the number of procedures and standardised them for easy implementation in the field. My thesis was used to make such recommendations to the programme and those recommendations were applied.'

HC – What is the process for bringing information to the national programme?

'Findings are presented in HSR report meetings. About once a year we plan HSR and carry it out, then the next year the investigators report back. From the findings of the HSR, decisions are made on what changes will be made to the programme in the next planning period. The programme runs according to five year plans but there can be modifications if HSR findings are thought to be too important to wait.'

HC – Who participates in that process?

'The programme manager, the regional officers, the principal investigators and the senior team leaders.'

HC – In retrospect, is there anything you would have done differently to have made the programme even better?

'Given the current resources available to us the programme is about as good as it can be. It is one of the best in our country, but one change that could have made the programme better would have been the inclusion of socio-economic rehabilitation. If there were more resources and political commitment with ministry approval, we could do more.'

HC – Do you feel that you could get permission for and commitment to introduce Socio-Economic Rehabilitation (SER)?

'Yes. I think for the future we can because there is a change in social and political status in our country so we may be able to do so. But we could only introduce SER it if we had resources. We do not have sufficient resources at present.'

HC – Are there any other points that have not been raised that you feel are important?
‘In our country we have targeted POD for high, medium and low endemic areas, but it may be that our resources could have been more effectively used if we had more emphasis on the high endemic areas. 80% of all cases come from those high endemic areas and so that’s where most of the POD need is too. When we plan we need to consider the prevalence.’

‘It’s very important to have proper facilities at health posts or sub rural health centres or rural health centres so that people can be brought there for ulcer care. Sometimes it is not convenient or hygienic to do ulcer care in clients’ homes. At such time we can ask the village volunteers to bring the clients to the centre.’

HC – If the patient is called to the Health Centre do his family members come too?
‘Yes we also teach the family members how to continue with the treatment of the wounds.’

HC – On the topic of volunteer workers: who are the volunteers to whom you refer?
‘We have trained community health workers, we have one health worker in each village. We also have auxiliary midwives where there are no midwives. These types of voluntary health workers support the BHS and the specialised staff.’

HC – Are they truly voluntary, unpaid workers?
‘They are genuine volunteers. They do not get any pay. The VHW (Voluntary Health Worker) gets 21 days training and that seems to be sufficient reward for them.’

HC – How useful and important have they been for the POD programme?
‘What they do is they collect patients and communicate with BHS. They will also take patients to health centres when this is necessary. Some of the very dedicated volunteers will check to see if the patients are doing self-care regularly.’

HC – Is it difficult to keep the volunteers motivated?
‘Most often they have their own job and so sometimes their first commitment is to that, but when we try to motivate them we find that some are more committed than others. It varies.’

Additional comments submitted by Dr Khim Maung Lay who had been the Team Leader in Pyay where POD had been piloted in the period from 2002 to 2006. Dr Khim Maung Lay’s comments were presented by Dr Tin Shwe

‘Strong political commitment from the divisional and township level of government (mid level) is essential.’

‘It is really important to have adequate training for both BHS and specialist staff before implementation. Training needs to include everything from self-care to recording and reporting. It is also important to keep updating the training on the basis of HSR findings.’
The service should be centred on the home: i.e. that the care givers (midwives) should take the service to the clients’ houses. Clients should not be expected to come to the health centres. This means that midwives need to be trained in all aspects of POD so that they can conduct nerve assessment and teach clients how to do self-care. The responsibility for supervision is shared between BHS and SLS. The junior leprosy workers will visit the clients once in three months but the midwives will visit once a month.

'It is essential to have a good recording system that gives a longitudinal perspective of the programme for review and evaluation.'

'It is essential to get good participation from family members. They did well in motivating and supervising clients.'

'Self-care is effective but you have to work hard to ensure patient compliance.'

**Discussion**

Although there is evidence of POD planning in Myanmar as early as 1970 it was in 2001 that a decision was made by the NLCP to intensify focus on POD and a request was filed with NLR for financial and technical assistance to do so. NLR, ALM and the UMNLCP entered into a tripartite agreement ensuring support for the pilot project. A POD pilot project was subsequently launched in 2002. The townships of Shwedaung and Thegone in Pyay District (Bago Division) were chosen as the location for that POD pilot project. The decision was based on the following factors:

- Adequate infrastructure to allow implementation of the strategies proposed.
- Experience and motivation of personnel in the Regional Leprosy Office for Bago Division.
- The area is considered representative of the 7 Divisions/States with the highest leprosy prevalence.

The essential objectives of the POD pilot project were:

- The collection and analysis of baseline data at the beginning and at the end of the pilot project period.
- Early detection and proper management of neuritis and reactions.
- Enablement of patients to do self care at home.
- Enable referral of complicated cases.
- Raising awareness of neuritis and reactions among patients and in the community.

Introduction into the POD Pilot project was initially limited to people who were currently being treated for leprosy or who had been released from treatment since 1998. Following the mid-term evaluation of the project a decision was made to include all people who had ever been treated for leprosy and had impairments due to the disease.

Following an evaluation of the POD pilot in 2004 another tripartite agreement was signed which secured support for an enhancement of the control programme with an emphasis on
POD. In the terms of the second tripartite agreement a commitment was made to expand POD activities to an additional 80 townships (mainly hyperendemic townships in Mandalay, Sagaing, Magwe, Ayeawaddy Division, and a few townships in Mon State and Yangon Division). Significant progress was made, however, so that by September 2010, the program had actually been established in 108 townships supported by ALM/NLR.

In 2004 JICA also assumed responsibility for assisting the programme to implement POD in 9 townships in Mid-Myanmar.

Detailed mid-term and end evaluation reports are filed with NLR and ALM. JICA presented evaluation findings at the 17th International Leprosy Congress. Findings from both programmes were similar. Details are not given here but where people had been included in the POD programs the results after at least two follow-up assessments confirmed that the impairment status of more than 80% of clients either improved or did not worsen.

Although ILEP and JICA support clearly enabled the programme to develop it was the personal commitment of staff in the BHS and SLS that was salient. Every village in Myanmar is served by midwives who have intimate knowledge of and relatively easy access to the people whom they serve. The midwives’ functions are many and the level of POD knowledge and skill that they have is basic, but in combination with the SLS the service that is provided to address leprosy is comprehensive.

Conclusion

The opinions and perspectives of the personnel interviewed for this investigation added depth to the findings of a survey, the results of which suggested that POD had successfully become a component of general health services in Myanmar. The following significant factors emerged:

- A cadre of Specialist Leprosy Service personnel were essential for providing referral services for problematic leprosy related issues (e.g. reaction), data collection, monitoring and supervision.
- Basic health staff (midwives and public health supervisors) should be trained to be grass roots implementers of POD.
- Good communication between the SLS personnel and the BHS personnel is crucial.
- Back-up services for complications (e.g. complicated ulcers) should be available at health centres designated to be the headquarters for SLS.
- Health system research should be routine and findings should be used to fine tune policies and practices.
- Competence and motivation at all levels (including volunteer workers) should be maintained through training.
- Sound political commitment, first at district (or equivalent) levels and then at central government levels should be secured (possibly through concerted advocacy).
- Partnership with INGOs is beneficial.

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References

Appendix 1: The Structure of the Health Care System and the interaction between General Health services and Specialist Leprosy Services in the Union of Myanmar

SMO - Senior medical officer
HA - Health assistant
LI - Leprosy inspector
ALI - Assistant leprosy inspector
JLW - Junior leprosy worker
MW - Midwife
PHS - Public
LHV - Lady

Health care system
General health services
Specialist leprosy services

Ministry of health
Department of health
Headquarters
General and specialist hospitals
State/division health departments
District
Township
Station hospital
Rural health centre
Sub centres
Sub centres
Sub centres

Deputy director
Regional leprosy officer
District medical officer
Team leader (technical advisor)
Township medical officer
LI/ALI (team supervisors)
SMO/HA/LHV/PHS1
MW/PHS2 (Implementers)
JLW (Field Coordinators)
Appendix 2: Contributors to the Focus Group Interview

Dr Tin Maung Aye  Deputy Director, Myanmar Leprosy Control Programme
Dr Tin Hlaing     Regional Leprosy Officer, Sagaing Region
Dr Than Win       Regional Leprosy Officer, Yangon
Dr Win Lwin       Regional Leprosy Officer, Bago Region
Dr Soe That       Senior Team Leader, Myangmya District
Dr Win Maw        Senior Team Leader, Mandalay District
Dr Oke Soe        Medical Officer NLCP, Naypyitaw
Dr Kyaw Kyaw Lywin Medical Officer NLCP, Naypyitaw

Dr Kim Maung Lay who had been the Senior Team Leader in Pyay District where the POD pilot project had been implemented was unable to attend but he sent his opinions by proxy of Dr Tin Shwe (ILEP Representative, Myanmar).