Community Participatory Methods in Disease Surveillance and Public Health in War-Affected Camps, and Its Potential Contribution to Peace Building

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Abstract

Using a combination of observational, operational data records, case-study narratives, and KAP survey methods, this paper explored how a district health system with the support of a Humanitarian Medical Relief agency sought to meaningfully engage members of a war displaced community in enhancing public health service provision through active disease surveillance and health promotion interventions. Results showed that participatory programming approaches led to the development of beneficiary driven health events that promoted community harmony and capacity building elements within conflicting communities. It is concluded that community participation, if meaningfully applied within humanitarian programming, can contribute to positive public health outcomes, ensure equitable coverage and encourage refugees to be agents of change within their own communities.

Key words: *Community participation, Disease surveillance, Complex Humanitarian Emergencies, Refugee Health, Peace through Health.*

Introduction

In accepting Primary Health Care (PHC) as a pillar of government health care policy with reference to the *Alma-Ata declaration* (WHO, 1978), and the *Ottawa Charter for Health Promotion* (WHO, 1986), all member states of WHO recognized the importance of 'involving communities' in health service program design, implementation and evaluation.[1-3] The meaning of the term 'community participation' is highly contested, and its forms of implementation are also open to a diversity of interpretations.[4-8] Community participation as an approach to health care may be viewed from two perspectives − as a demand from communities or as a strategy for professional practice.[8] As a 'means', participation can be viewed as a process that ensures co-operation and collaboration by communities within public health programs.[4] The rationale for such an approach is a technocratic one, which views participation as a means of ensuring successful interventions/outcomes for beneficiaries. Participation as an 'end' is seen as a goal in itself, manifesting as the 'empowerment' of communities in their acquisition of the skills, knowledge, and experience.[4] Thus, participation can be seen as a technocratic process that serves a program's purpose, or manifests within a pedagogical or socio-ecological approach where participation is crucial in equitably reshaping power/empowerment towards program beneficiaries or communities.[6]

The notion of power and how it is reshaped between the health care provider and health care beneficiary is crucial in participatory health action.[4,5] These theoretical frameworks are important in understanding meaningful participatory practice. For instance, a nominal form of involvement may manifest in convincing refugees to dig drainage soak-pits as a contribution to a water supply scheme. However, people's enthusiasm for a project depends much more on whether they have a genuine interest in it, rather than whether they merely participated in its construction.[9] Others may also argue that participation for the project managers falls within a reductionist framework where a token number of consultative meetings with the beneficiary community, gives the appearance of but not the substance of meaningful participation. Therefore participation in health ranges from people passively receiving benefits from health programs, to people actively making decisions about the program policies and activities.

Evidence and Impact for participation

Critical reviews of participatory approaches to development by the World Bank,[7,10] Canadian International Development Agency[11] and United States Agency for International Development (USAID),[12] concluded that participatory methods in program planning, design and delivery yielded the greatest degree of success and sustainability.

Within a humanitarian relief paradigm, there is persistent debate that such participatory methods are inappropriate due to 'a lack of time'. However, according to the World Bank study, while participatory methodologies may require "greater upfront investment in staff training and operations expenditures" (up to 15% throughout the life of programs), overall costs average lower than in programs that "do not rely on local capacities".[7,10] Despite these inherent advantages, participatory methodologies have not been widely embraced in humanitarian or disaster development practice.[7]

Importance of community participation in health care delivery

Relief programs are often criticized by those who work within a development paradigm as offering little opportunity for community participation and development of local structures.[13] This perception becomes more acute within a medical domain, which is commonly viewed as an 'expert based' domain, with limited scope for community participation in PHC delivery and decision making.[5,6] Conversely, there are also many push and pull factors that prevent communities from engaging in participatory models of health care.

While research exploring community participation in PHC programs within conflict-affected states are scarce,[13,14] public health research from development contexts such as Tanzania,[15] Bangladesh,[16] Bolivia,[17] Brazil[18] and Nigeria[19] revealed a number of barriers to meaningful participation. These include poverty, time constraints, social inequality, dependency relationships, low self-esteem, psychosocial trauma, poor governance and a lack of a 'sense of community'.

Even though such barriers to meaningful participation exists, overstretched public health systems in war-zones responding to mass population displacements, may benefit with models of refugee health care where meaningful engagement, rather than the mere 'delivery' of services to beneficiaries

exist. Within this framework of empowerment, beneficiaries become more than mere passive recipients of aid, or conjugates of aid delivery. They transform to active participants in program implementation. Humanitarian agencies may provide a crucial role in building such partnership models between affected communities and the district level public health system.

Contextual Analysis

Violent civil conflict between the Sri Lankan Armed Forces, Para-military groups and the Liberation Tigers of Tamil Elam (LTTE) in Batticaloa district, in Sri Lanka's Eastern province, resulted in over 180,000 people being displaced from their homes in 2007.[20] The war displaced were housed in 96 Internally Displaced Camps (IDP) managed by humanitarian agencies and local government authorities. The immediate public health concern was the threat of outbreaks of communicable diseases related to poor water and sanitation facilities. The health threats posed by an overstretched public health system, that was only beginning to recover in the aftermath of the 2004 Tsunami disaster, placed enormous demands on health workers in the conflict zone.

Public Health Response

The humanitarian health sector responses that evolved during the crisis were co-ordinated through weekly meetings chaired by the Regional District Health Services authority (RDHS). The major intervention arms directed by the health sector within the conflict zone were as follows:

Curative:

- Deployment of Medical Mobile Clinics to affected camps via various Non-Governmental Organizations (NGOs)
- Mobilizing Medical offices of health, Public Health Inspector (PHI) and Public Health Midwifes (PHM) within affected zones to ensure public health service coverage
- Establishing an emergency referral network in IDP camps
- Co-ordinating health facility reconstruction and via NGOs/UN/Donor groups.

Preventative/Promotive:

- Camp based Maternal and Child Health program, including antenatal clinics (ANC) and 'well-baby' clinics
- Establishing a district-wide network for enhancement of health promotion in IDP settings
- Disease surveillance system and outbreak response measures
- Maintaining Water quality through PHI testing and sanitation monitoring
- Co-ordinating the distribution of hygiene kits, well baby kits etc in camps
- Ensuring advocacy/technical advice across humanitarian response clusters: an Integrated Water and Sanitation (WATSAN) program, emergency food, shelter and protection nodes.

To meet these public health demands of both the conflict and Tsunami affected populations, the health sector authorities appealed to the international community for humanitarian assistance. Many post-Tsunami development programs immediately remobilized to assist the 180,000 displaced within the conflict zone.

Participatory Approach for IDP Health Intervention

Merlin, the United Kingdom based medical aid agency embarked on a program that sought to engage displaced communities in a meaningful way for the delivery of health services in the IDP camps (20). By working in partnership with the local health authorities, government administrators and leaders of war-affected communities, "camp health committees" were formed. The major goal of this joint community health partnership was a PHC intervention program at each IDP camp level that involved the implementation of:

- A community based "Early Warning" disease surveillance and outbreak response (EWARN) system
- An Integrated Water and Sanitation (WATSAN) and environmental health management program

This paper reported the contribution and impact community participatory methods had in enhancing communicable disease surveillance and outbreak response activities at the camp level. A detailed step-by-step analysis of the implementation process and public health impact of the complete intervention strategy have been documented elsewhere.[20]

Limitations in Existing Disease Surveillance System

Although Sri Lanka has a robust disease surveillance plan orchestrated by a centralized epidemiological unit, but limitations in scope and coverage still exists in conflict affected districts of the North East.[21,22] These stressors become more acute during times of mass population displacement.

The PHI is the key focal point for disease surveillance at camp level that helps in undertaking case detection, sample collection, reporting and outbreak response measures. The PHI is also expected to undertake an exhaustive list of activities for environmental health protection, ranging from water quality testing, vector-born disease control, relief-food inspections and WATSAN monitoring (see Figure 1). In addition to these camp specific roles, the PHI is responsible for medical inspections in school, rabies control activities and is the regulatory authority on maintaining health standards across food outlets within a district. Focus group discussions with PHI's as part of a major research study currently being undertaken by authors revealed that their capacity to maintain effective surveillance and other health interventions were compromised due to their excessive IDP camp caseload.[23]

Community Participatory Early Warning System

Working in partnership with the regional health directorate, Merlin devised a program that sought to enhance the capacity of IDPs to support PHIs and local health authorities improve disease surveillance and outbreak response in camps. An early warning system (EWARN) was adapted for selected communicable diseases such as diarrhoea, hepatitis, conjunctivitis and varizella zoster. The program involved training approximately 390 community based IDP health volunteers (CBVs) across 27 camp settings with an intensive 3 Phase modular program,[1] covering themes of health promotion, environmental health management, 'syndromic' case detection and outbreak response measures. This enabled a more robust system where CBVs were able to refer suspect cases to visiting PHI and mobile medical teams in a pro-active manner (see Figure 1).

Community Health Volunteer Worker Competencies

All CBVs undertook an intensive three-tiered training program which aimed at delivering the following competencies:

- Case detection using World Health Organization's (WHO) 'Syndromic' based approach for selected communicable diseases relevant to IDP context (Diarrhoea, Conjunctivitis, Hepatitis -Acute Jaundice syndrome, Chicken pox, Dengue and Chikengunya)[24]
- Outbreak management strategies at camp level
- Maintaining a camp based sentinel disease surveillance system
- Maintaining a camp based WATSAN (water and sanitation) surveillance system
- Identifying the action taken to respond to various types of diarrhoeas and basic signs of dehydration (both in infant and adult)
- Home based treatments for dehydration using Oral Dehydration Therapy (ORT)
- How to assist PHI in contact tracing, source identification at camp level, case isolation and community risk communication strategies
- Health promotion messages and community mobilization strategies with a focus in preventing communicable diseases– special emphasis given to food preparers, children and adolescents.
- Maternal and Child health care: promotion of exclusive breastfeeding, assisting PHM in ANC clinics.
- Mobilizing community for medical mobile clinic interventions
- Solid waste management system activities and monitoring
- Health advocacy training in order to effectively advocate to local authorities/NGOs in resolving camp based health and social issues

On average a ratio of 20 CBVs per 1000 displaced people were maintained across 27 IDP settings. CBVs were mainly young people between the ages of 18 to 30 years of age, and more than 65% were female. The CBVs mobilized themselves into units such as health promotion team, water team, solid

[1] *The training package, published as a CD-ROM is available from authors upon request (English and Tamil Language)*

waste management team and surveillance team in order to conduct these tasks (Figure 2).

A water and sanitation (WATSAN) surveillance mechanism were also implemented with support of PHIs and CBVs. Many CBVs continued to show commitment and dedication to absorbing public health knowledge and translating this into field level interventions to respond to daily health risks.

Purpose of Study

The main objective of this paper was to explore the impact of a public health intervention strategy catalyzed during a humanitarian crisis in Sri Lanka's East that sought to engage war-affected communities in enhancing/building communicable disease surveillance systems, and undertaking health promotion activities in displaced camp settings.

Methods

A combination of observational case-study narratives, epidemiological surveillance and Knowledge-Attitude-Practice (KAP) survey methods were used to explore the impact of the implementation of a community participatory disease surveillance system and health promotion intervention within war affected IDP camps in Sri Lanka's Eastern Province.

The quantitative data for assessing the intervention were derived from the following sources:

- Ministry of Health Routine Epidemiological surveillance data for Batticaloa District (March 2007 to November 2007). Key variables examined: weekly records of communicable disease notifications for such diseases as diarrhea and varizella zoster. The case definitions for infectious conditions under public health surveillance were derived from the Sri Lanka Ministry of Health Epidemiology Unit.
- The Merlin Batticaloa Internally Displaced Camps (IDP) Early Warning (EWARN) project database (March 2007 to November 2007). The database was developed in partnership with Batticaloa Regional Director of Health Services, humanitarian agencies, local camp management staff and war-affected IDPs specifically to track the disease surveillance patterns and health promoting interventions across 27 IDP camps nestled within 3 local administrative divisions.
- Observational data from Merlin Batticaloa IDP EWARN project database included both process and output indicators that were derived from ongoing monitoring systems. These were collected by field based CBVs and collated by Merlin program staff. Key variables examined: Number of trained CBVs per camp, Number of Health Committees established at each IDP camp, number of Oral Rehydration Salt (ORS) pack administered/distributed, number of case-referrals by CBVs to primary health care workers, number of heath promotion/environmental health interventions over reporting period.
- KAP surveys on infectious disease transmission, outbreak control and health promotion intervention strategies were conducted with 390 internal displaced people trained as Camp Based health Volunteers (CBVs).

The KAP surveys were developed by a team of Merlin public health specialists. The survey instrument was developed in English and then translated into Tamil by two of the Merlin Public Health specialists. The translated survey was further reviewed by a Public Health Academic at Jaffna University and an RDHS representative before being rapidly pre-tested within a single IDP camp setting (due to time constraints). The survey instrument consisted of 20 questions which assessed CBV's on knowledge of contextually relevant communicable disease transmission and control strategies (Module 1), and secondly, Water & Sanitation promotion and environmental health management practices (Module 2). Each IDP camp contained an average of 20 CBVs. Surveys were conducted in all 27 IDP settings. All CBVs provided written informed consent and the study protocol and ethical clearances were obtained by University of Jaffna, Sri Lanka. Data was scored using a set of responses developed from standard protocols established by the World Health Organization Communicable Disease Control field manual.[2]

[2] Connolly, M. A. (2005) WHO Communicable disease control in emergencies: a field manual. World Health Organization Publications.

The pre-tested KAPB self-administered surveys were disseminated to all CBV's prior to a comprehensive training program organized by Merlin, the World Health Organization and trainers from the Batticaloa District Health Cluster. The CBV's were followed up after their training for a period of 4 months before the survey instrument was repeated. All 390 CBV's remained active in the IDP camps and participated in the follow up KAP survey. Data entry and analysis was undertaken using Microsoft Excel software (version 2007).

The qualitative data for this report were derived from field reports, minutes of fortnightly co-ordination meetings with CBVs and case-notes from Merlin program managers. A CBV camp database was maintained by Merlin public health staff which contained weekly records of all CBV activities. The observational data relating to the EWARN program implementation, community development initiatives, emerging trends and practices were also recorded in detailed reports by Merlin health program manager and 12 project officers. These reports were assessed by authors, and further clarified by interviews with project staff.

Results and Discussion

Assessing the Impact of Community-based EWARN IDP Surveillance System

The ultimate goal/impact of any humanitarian health intervention is to ensure health protection through reduced morbidity and mortality. Surveillance systems are crucial not only in assessing the burden of disease but in responding to outbreaks.

To assess the delivery of the above described health promotion and surveillance interventions, authors compared the surveillance data obtained from the EWARN program with the districts routine reporting system. The districts' routine epidemiological surveillance systems[3] were unable to capture weekly returns in a systemic manner, and thus true burden of disease was unknown.[26] In contrast, in IDP settings that implemented the participatory disease surveillance system (EWARN), epidemiological data were collected on a weekly basis over a 9 month period until IDP re-settlement in November 2007. Process indicators from camp management and Merlin records indicated high levels of ORT use and referrals to PHC workers. Such data were useful for health planners and aid agencies in meeting the public health demands of the displaced populations.

These findings consolidate earlier assumptions on the over-stretched capacities of key public health staff at times of mass population displacement. These challenges become even more acute in war affected zones with even more limited human resource capacities.

Participation in emergencies usually tends to concentrate on consulting beneficiaries about their needs, rather than entrusting beneficiaries with control over the programme. In the current program intervention, project planners engaged beneficiaries as active participants in the implementation process and achieved a more robust reporting system.

The surveillance chart (see Figure 3) was maintained by the CBVs and management at each camp, and this proved useful to visiting medical mobile units and primary care staff for active surveillance and follow-up investigation. It is important to note that while there were no major outbreaks, small sporadic outbreaks occurred in some IDP camps (see Figure 3). When reported data were analysed, a decline in overall disease burden from the inception of the IDP EWARN program could be observed. However extrapolating or attributing this positive public health impact to a singular program, in the absence of any controlled study is difficult.

Assessing the Knowledge and Practices of CBVs

The KAP surveys were used to capture basic public health knowledge and practice strategies for trained CBVs within the IDP camp settings. As indicated in Figure 4, a significant increase in core knowledge and practice strategies across all areas of competency was observed in the trained CBVs. The qualitative data from weekly reports (independently verified by camp managers), supported the results from the KAP surveys. Of particular importance was the active role CBVs played in implementing good practice measures to control vector born diseases. Health sector co-ordination meeting minutes also made regular reference to advocacy from CBVs to Primary health care workers in relation to solid waste management in camps.

[3] The routine system failed to collect regular surveillance data for the period beginning March to November 2007 (the reporting period of the EWARN program).

Community Harmony Building Initiatives Initiated through Community Health Volunteers

In a number of camps, the CBVs were instrumental in initiating innovative methods for promoting public health messages. In 5 camp settings, the CBVs formed 'health promoting *edutainment* groups' that conducted performances to both IDP and host communities on a themes ranging from child protection, to issues arising from alcohol abuse and dengue prevention. Most of these activities were funded through various NGOs, and the health communication messages were screened by PHIs and Merlin staff before implementation. One particular CBV group organized themselves as a professional song and dance troupe and were invited to perform at various host-community events, including an opening ceremony of a newly built hospital. These activities had a positive impact of boosting their self-confidence, resiliency and creating livelihood opportunity during their displacement.[27]

CBVs in other camps were also the protagonists of community harmony building initiatives called "*Health, Cultural and Sports Festivals*". The first such event of its kind was held in a volatile conflict zone bordering a Muslim and ethnic-Tamil community. There had been many outbreaks of communal violence within these communities post-IDP arrival. After a period of extensive consultation with both religious and civil society leaders, the Camp managers and CBVs organised a major health festival involving children from both IDP camps and surrounding host-community schools. During a staged cultural event, the children explored (through speech and drama performances) the perceived roles professionals (e.g. doctors, police officers) and their potential to transform it. CBVs also conducted 'health quiz shows' and forum theatre performances to promote core health messages learnt through their training. The community reference group that organized the event deliberately avoided all political sources of influence/funding in holding the event, and partnered with humanitarian organizations (such as Merlin and United Nations) to ensure the event was kept a non-sectarian and non-denominational one. The major emphasis was a health promoting 'healthy communities' model.

Inspired by this example, CBVs in other IDP camps undertook similar community events with support of humanitarian actors, adapting the themes and messages according to their own needs and capacities. For instance, 'health festival events' in other settings focussed on senior citizens in their camp, whilst others payed homage to role and sacrifice of mothers. These CBVs who inspired such community health festivals received acknowledgment and support by their own peers and communities. As revealed in field reports and focus group discussions[23], such community recognition further empowered and motivated CBVs to harness self-directed health initiatives.

Conclusion

Using a combination of observational, operational data records, case-study narratives, and KAP survey methods, this paper explored how community participation may enhance selected public health services in a resource poor war zone, and how such participatory processes contributed to community harmony building initiatives. The community participatory approach described in this paper, yielded to a more technocratic approach, where trained IDP community members were involved in the implementation and monitoring of a public health program in order to achieve specific health goals (the EWARN and health promotion IDP project). However, the program embedded and enabled within its delivery the freedom for self-directed initiatives from participating CBVs, such as the Camp Health Festivals. These manifestations may relate to the 'ideological' process of participation as described by Rifkin,[6] where program beneficiaries actively reshape decisions on program activities.

A key theme to emerge is the role humanitarian agencies can play in enhancing and stimulating participatory approaches to public health service provision, thereby creating an enabling environment for beneficiary participation. Although challenging and time-intensive within a relief paradigm, such representative forms of participation, if meaningfully applied within humanitarian programming, may affect positive public health outcomes, ensure sustainable coverage and encourage affected people to be agents of change within their own communities. This paper also brings to light the important issue of promoting evidence based practice/uptake within complex humanitarian emergencies, which are characterised by rapid staff turnover and the perception that there is little time to learn lessons and promote longer term health systems development.[25]

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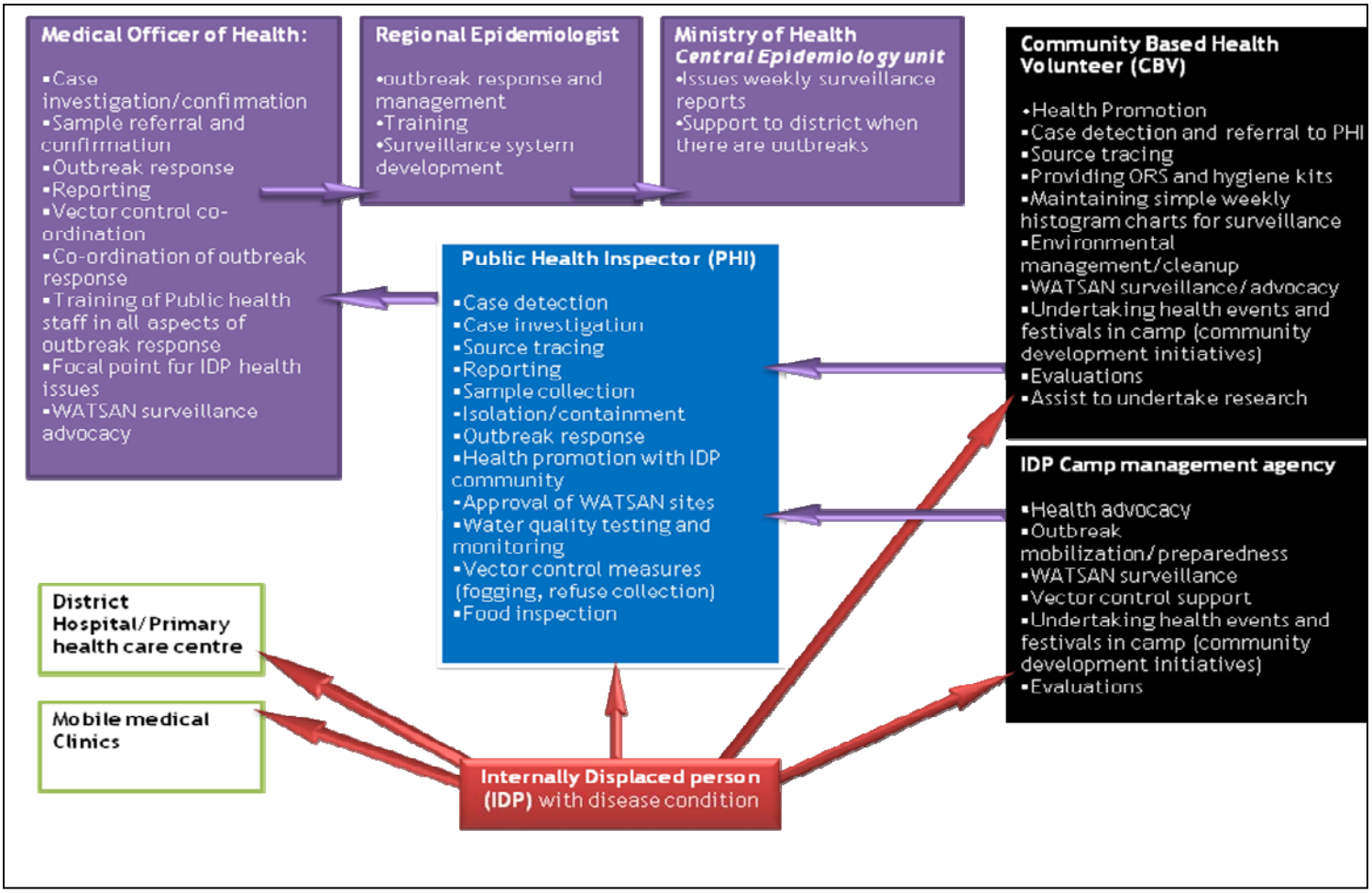


Figure 1: A schematic diagram showing enhancement of existing surveillance system by CBV and IDP camp management participation. The routine disease surveillance system includes the public health inspector reporting to the medical office of health at the local district level, who in turn reports to the regional epidemiologist. The final reports are collated at the Centralise Epidemiological unit. The PHI is responsible for undertaking passive surveillance activities for both IDP camps *and* the host community within a defined catchment area. The IDP EWARN system builds capacity of this existing system though the introduction of trained Camp managers and IDP's to facilitate an active case detection system. Referral of IDPs with suspect disease conditions are referred to visiting PHIs or Medical Mobile Clinics. The CBVs and camp managers work in partnership with the PHI for WATSAN (Water and Sanitation) and health promotion activities to boost preventative health care provision.

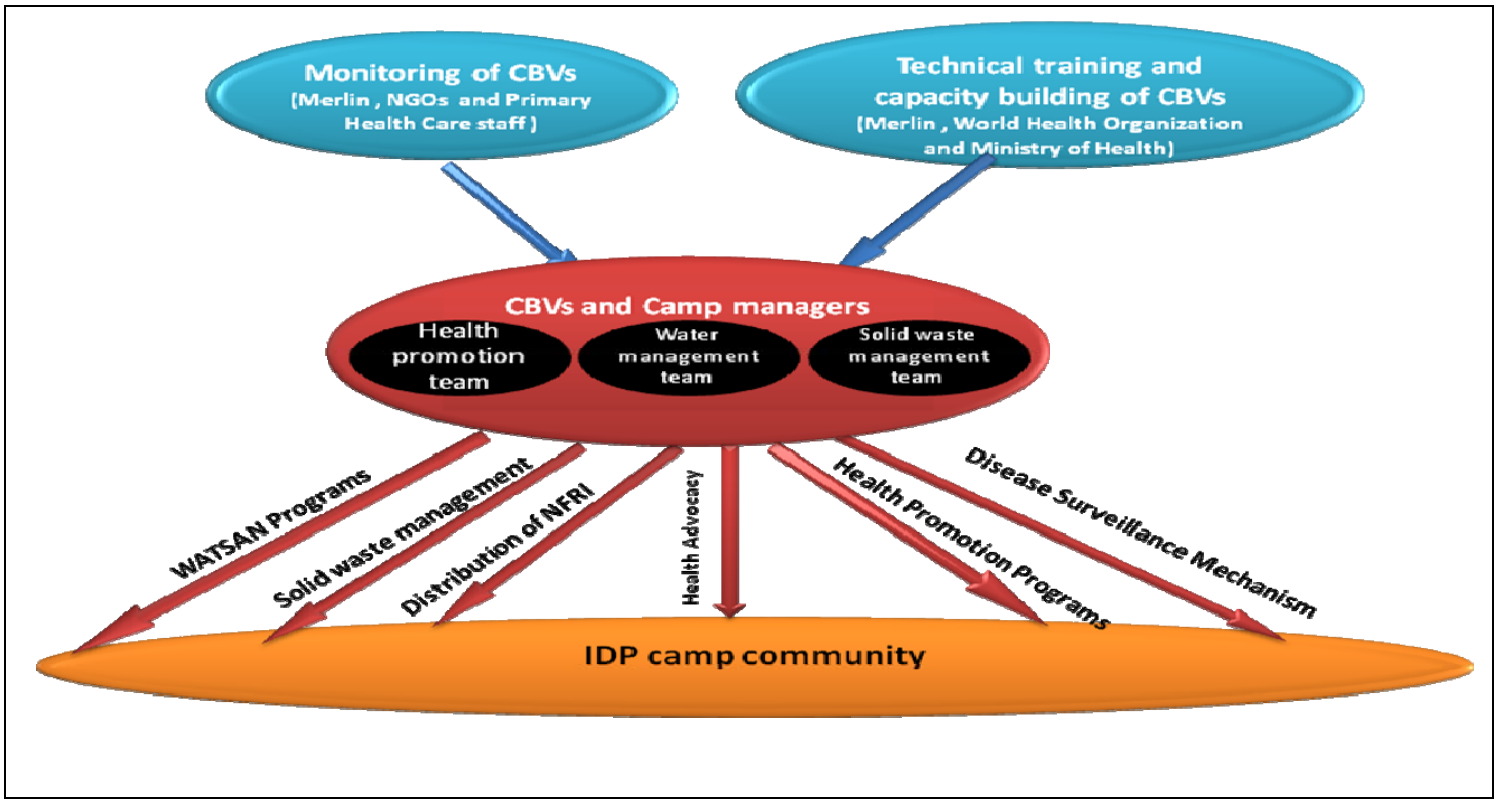


Figure 2: Co-ordination dynamics between key-stakeholders of the IDP camp health program. The CBV and camp managers were involved in supporting a range of health and community development programs. The training and development of these CBVs were done through UN, Ministry of Health and INGO (Merlin). The local NGOs in partnership with Merlin and PHC staff provided the ongoing monitoring and support of the CBVs. Please note that all 3 teams are responsible for the disease surveillance activities.

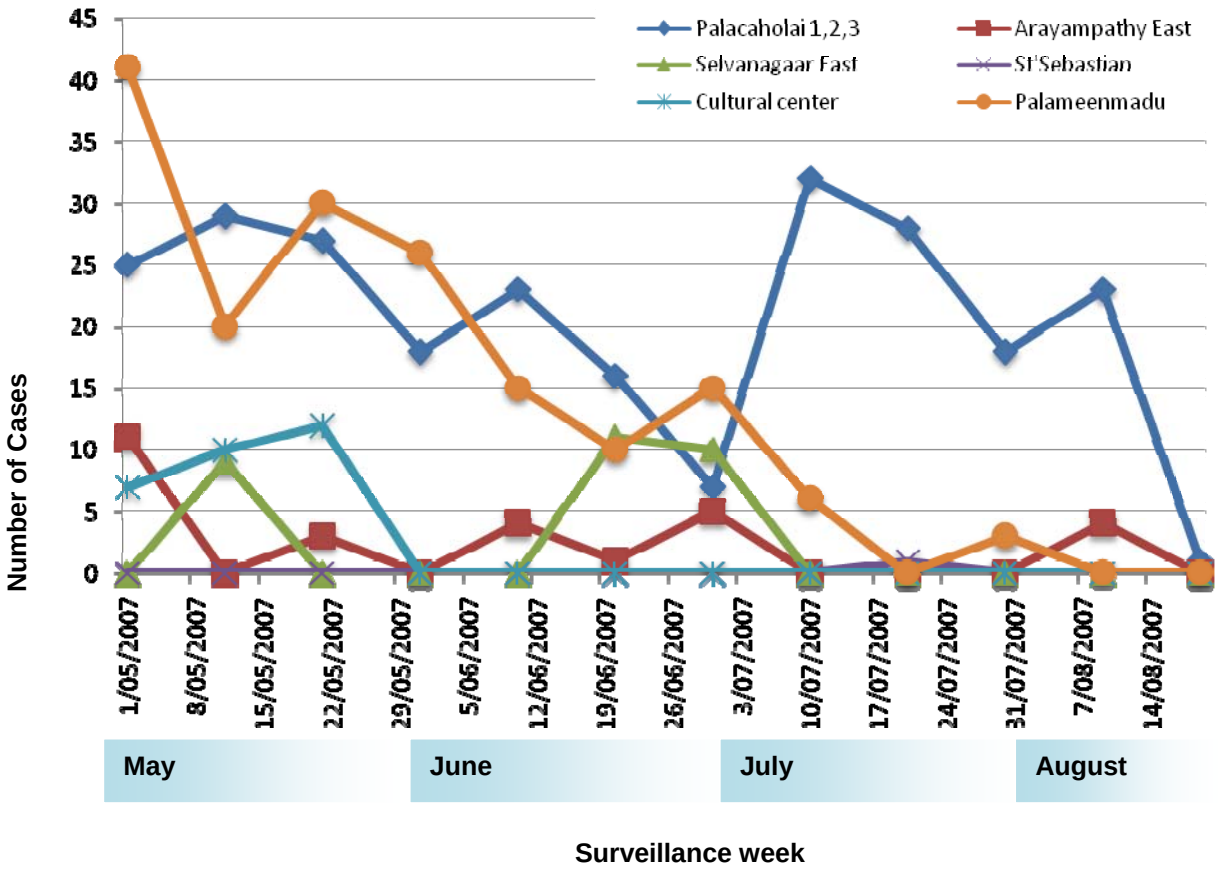
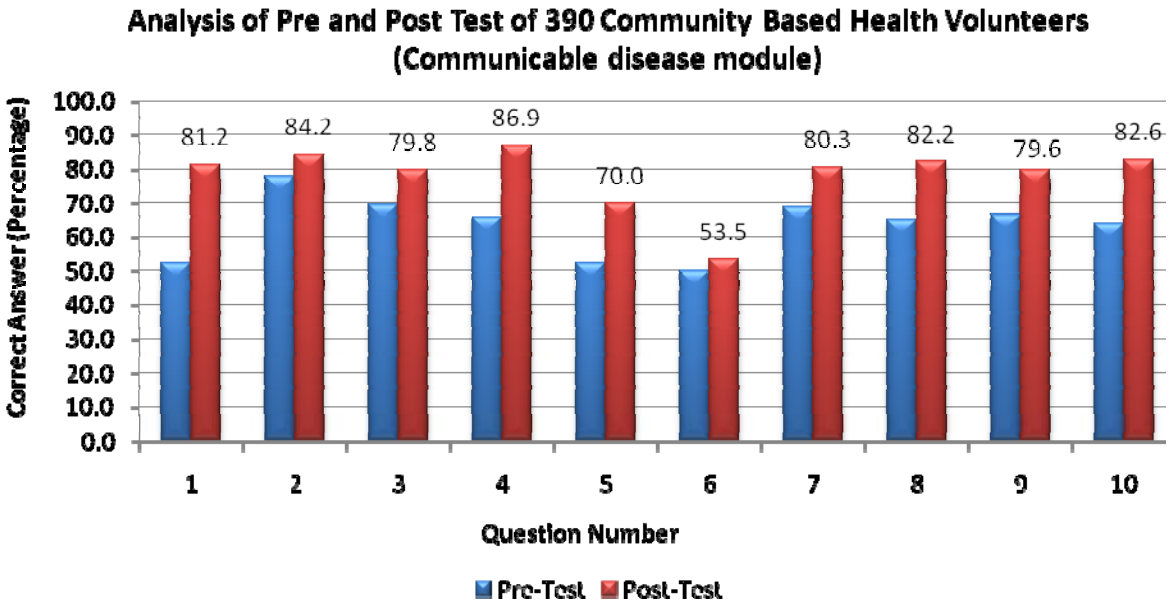


Figure 3: A four-month snapshot of the Diarrhoeal disease burden in 8 selected IDP camps where IDP EWARN project was implemented. Disease burden varied in each camp over the duration of the reporting periods, however the case-load dropped in many camps over time. A diarrheal outbreak was reported in the Camp named "cultural centre' and investigations by PHI revealed the possibilities of a contaminated food source. Please note "Palacholai" comprises of 3 IDP camps which were included into one reporting cluster.



Question Number (correlates to above chart)

1. How does conjunctivitis spread?
2. What are the symptoms of conjunctivitis?
3. How does the Chicken pox virus spread?
4. How do we prevent the spread of Chicken Pox in camps?
5. What are the various types of Diarrheal disease?
6. List 2 action points to be taken as a CBV in responding to cases of Dysentery?
7. How can the Hepatitis-A virus spread in a camp population?
8. What are symptoms of Hepatitis?
9. How does Malaria spread?
10. What action can you take at camp level to prevent the spread of Dengue Fever?

Figure 4: **Analysis of KAP-survey results of 390 Community Based Health Volunteers in the Communicable disease module.** On average, the knowledge surrounding diarrheal disease and case-management practice of those presenting with dysentery were the weakest in the CBVs across both pre and post tests. Despite this, the communicable diseases knowledge showed significant improvement across all questions.

Figure 5 Two of Merlin's Public Health staff performs a traditional song and dance with displaced children in one of the IDP camp community health festivals (Photo taken by primary author with consent, September, 2007).