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CONTENTS

Editorial

- Making “prevention and preparedness” a recovery priority: lessons from the response to the 2015 Nepal earthquake 107

Review

- Opportunities and obstacles in child and adolescent mental health services in low- and middle-income countries: a review of the literature..... 110
Dutsadee Juengsiragulwit

Original research

- HIV drug-resistance early-warning indicators and quality care in India: preliminary findings from a pilot study in Pune city..... 123
Manisha Ghate, Dileep Kadam, Nitin Gaikwad, Subramanian Shankar, Shraddha Gurav, Girish Rahane, Sukarma Tanwar, Bharat Rewari, Raman Gangakhedkar
- Lessons for addressing noncommunicable diseases within a primary health-care system from the Ballabgarh project, India 130
Ritvik Amarchand, Anand Krishnan, Deepika Singh Saraf, Prashant Mathur, Deepak K Shukla, Lalit M Nath
- Regional variation in maternal and childhood undernutrition in Bangladesh: evidence from demographic and health surveys 139
Masuda Mohsena, Rie Goto, CG Nicholas Mascie-Taylor
- Exploring the factors that influence the perceptions of disability: a qualitative study of mothers of children with disabilities at a community-based rehabilitation centre in Sri Lanka 150
Michel D Landry, Sudha R Raman, Elise Harris, Layla Madison, Meera Parekh, Cecile Banks, Huda Bhatti, Champa Wijesinghe
- Tobacco-promotional activities in rural Sri Lanka: a cross-sectional study of knowledge, exposure and responses among adolescent schoolchildren..... 159
E Madhurangi Perera, Nalika S Gunawardena

Access to free health-care services for the poor in tertiary hospitals of western Nepal: a descriptive study..... 167
Preeti K Mahato, Giridhari Sharma Paudel

HIV prevalence in blood donors and recipients in Pakistan: a meta-analysis and analysis of blood-bank data 176
Bushra Moiz, Barkat Ali, Muhammad Hasnain Chatha, Ahmed Raheem, Hasan Abbas Zaheer

Policy and practice

Feasibility of implementing an integrated tool for improvement of treatment quality and early-warning indicators for HIV drug resistance: a pilot study of centres in India 184
Bharat B Rewari, Nicole S Seguy, Sukarma SS Tanwar, Po-Lin Chan, Vimlesh Purohit, Pauline Harvey, Dongbao Yu, AS Rathore

Impact of rubella vaccination on elimination of congenital rubella syndrome in Sri Lanka: progress and challenges 189
Deepa Gamage, Geethani Galagoda, Paba Palihawadana

Towards elimination of parent-to-child transmission of syphilis in India: a rapid situation review to inform national strategy 197
Vani Srinivas, Prasad LN Turlapati, Anil K Bhola, Aman K Singh, Shobini Rajan, Radha S Gupta, Sunil D Khaparde

Landscaping capacity-building initiatives in epidemiology in India: bridging the demand–supply gap 204
Sanjay Zodpey, Anuja Pandey, Manoj Murhekar, Anjali Sharma

Letter

Innovative use of social media platform WhatsApp during influenza outbreak in Gujarat, India 213
Bhagyesh Shah, Shuchi Kaushik



Making “prevention and preparedness” a recovery priority: lessons from the response to the 2015 Nepal earthquake

The frequency of natural disasters, and regularity of tragedies resulting from conflict and terrorism, is increasing at a troublesome pace worldwide. There was a three-fold increase in the number of global natural disasters during the period 2000–2009 compared with 1980–1989,¹ and the cost of humanitarian responses to disasters was reported to be US\$ 17 billion in 2005.² Although, as a global community of citizens, we may hold some implicit or explicit responsibility for these events, they are mainly beyond our control, and often occur in communities that are least prepared to manage the health and population-related outcomes. The region of South Asia appears to have a relatively high frequency of natural disasters and very high mortality resulting from these events. Approximately 40% of global deaths due to disasters during the decade 2004–2013 were from the countries of the World Health Organization (WHO) South-East Asia Region.³ The South-East Asia Region is no stranger to disasters resulting from natural hazards, as evidenced by the major disasters including the Tsunami of 2004, Cyclone Nargis of 2008, Sumatra earthquake of 2009, and Thailand floods of 2011. The most recent event that has garnered global attention has been 2015 Nepal earthquake(s).

THE INEVITABLE: NEPAL EARTHQUAKE(S) OF 2015

Nepal is a small land-locked nation bordered by China and India, and has a population of about 29 million. It is considered one the poorest countries in Asia, and in 2014 ranked 145th



WHO/A. Khan

Medical staff attending to triaged patients outside an overflowing hospital in Kathmandu.



WHO/A. Khan

Trained volunteers transferring injured during the second aftershock.

out of 187 countries on the United Nations Development Programme’s Human Development Index, placing it in the bottom quartile in terms of its standing in international development.⁴ The geography of Nepal includes eight of the highest mountain peaks on earth (including the famed Mount Everest) on the northern border, and some of the most fertile land in the region along the southern border, known as the Terai. Despite its tremendous natural resource, Nepal has struggled with high rates of poverty (about 30% of the population live on less than US\$ 2 per day), and is still recovering from a decade-long civil war that ended in 2006. Moreover, close to 80% of the population lives in rural settings, where access to health or social infrastructure is a challenge. Predictions of a major earthquake in Nepal have been made for decades, and, tragically, these forecasts became a reality in the spring of 2015.

WHO/A. Bhatiajevi



WHO staff delivering risk-communication messages for mothers.

On 25 April 2015, and then again on 12 May 2015, massive earthquakes measuring 7.8 and 7.6 respectively on the Richter magnitude scale unleashed tremendous damage to the physical infrastructure of the country, and, more importantly, resulted in thousands of casualties, injuries and displaced populations. The epicentres of the earthquakes were first in the Gorkha district, and then in the Sindupalchok district, both located at the periphery of the capital city of Kathmandu. Although there are always challenges in collecting reliable and valid data following a natural disaster, the United Nations Office for the Coordination of Humanitarian Affairs has reported that there were approximately 8500 casualties, more than 22 000 people injured, and hundreds of thousands of internally displaced persons.⁵

PREVENTION AND PREPAREDNESS LEADS TO BETTER RESPONSE

Given the predictions of an impending mega-earthquake, the government of Nepal and its long-standing local and international partners had developed disasters-preparedness planning, processes and protocols well before these recent events. Various protocols – from a nationally agreed earthquake scenario to specific sectoral plans of action – prepared the country for such an event, in particular, in the capital Kathmandu. Mass-casualty management and preparedness-related protocols were in place at the time of the earthquake, and although it is somewhat difficult to measure objectively, this level of preparedness probably resulted in a more effective and coordinated response.

For close to a decade, WHO has been working with the Ministry of Health and Population on keeping health facilities in Nepal as safe as possible in the event of disasters. Together with experts, a methodology to assess the structural integrity of key hospitals was accepted and experts were trained around these guidelines.^{6,7} Hospital staff in different districts of the country were trained in management of mass casualties, but improving the hospital infrastructure was challenging, since it was a capital-intensive process with few donors forthcoming. In 2012, the Nepal Risk Reduction Consortium

was established,⁸ and provided the impetus for establishing one of its flagship projects: “Safe hospitals”. This was a unique whole-of-government approach, and coordinated the work by development partners. As a result, six hospitals in the Kathmandu Valley were re-assessed, and non-structural and structural interventions were carried out. In many places in the city, through various organizations, medical and essential supplies were pre-positioned. The Health Emergency Operations Centre was established for the Ministry of Health and Population, as a separate modular structure to coordinate information from events. It was already in use 2 years before the earthquake during the response to floods in the monsoon season. In essence, at the time the earthquake happened:⁹

- the Ministry of Health and Population was operational within hours of the event;
- pre-positioned stocks were released immediately, to ensure supplies in hospitals;
- the six main hospitals in Kathmandu could absorb the load of patients from the Kathmandu Valley and surrounding districts for cases requiring specialized procedures;
- district hospitals in the Kathmandu Valley, especially those not completely damaged, could manage the influx of patients, owing to:
 - training in management and triage of mass casualties;
 - district-level contingency planning;
- rapid response teams trained previously in outbreak investigation were mobilized as soon as any report or rumours of possible epidemics were received.

The response was able to address the priority health issues of: injury and disability; psychosocial support and mental health; continuation of basic health services; and improved surveillance, in a more efficient manner.

As Nepal is a country prone to regular monsoon floods and landslides, the response system has also been tested previously. While the earthquake was an event of much larger scale, the investments in prevention and preparedness has also paid off

WHO/M. Vurens



WHO team crossing the bridge to reach a far-flung community.

in terms of being able to absorb all external assistance that has come forward, with 130 health partners and 110 foreign medical teams, and 50 national medical teams there at the height of the emergency. Donations in kind and financial aid in millions poured in, and US\$ 4.5 billion was pledged for recovery.⁹

SCALING UP FOR A “DISASTER-PROOF” HEALTH SYSTEM

The damage to the health systems of Nepal is severe. In the 14 districts affected by the earthquake, 85% of health facilities are damaged; 484 health facilities are destroyed and another 474 are partially damaged. A total of 2.8 million people have been left homeless. With this devastation, the world has rallied to provide much needed support and there is an opportunity for a rethink before rebuilding. Clearly, what is needed is to provide further input related to prevention and preparedness, for a more resilient health system. This includes more health facilities that will withstand another earthquake of similar magnitude, not just in Kathmandu but also in the other districts; more trained staff to manage casualties; more trained psychosocial first aiders among these facilities; well-equipped rehabilitation specialists and physical therapists; established and functioning auxiliary health facilities such as laboratories and blood banks; and, more importantly, communities that understand the risks and basic health response. In essence, a health system is required that copes with the hazards it faces by virtue of its geography and sociopolitical-cultural context; this is a key outcome of the *Sendai Framework for Disaster Risk Reduction*,¹⁰ that countries, including Nepal, have committed to and signed.

The tragic events that occurred during the spring of 2015 mark a turning point for Nepal – we must use these events to examine what worked well and where specific improvements in disaster preparedness and response could and should be made in the future. It is only through careful and deliberate assessments, and then sharing of lessons learnt, that we continuously improve our local, national and regional responses to natural disasters. Sadly, it takes a disaster to prove that investments in health systems geared up for disasters pay off. Nepal has shown that scaling up prevention and preparedness in the health sector can

save lives, and doing more of it in very vulnerable peripheral areas is the way forward into a future where further such events are likely to be experienced.

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Opportunities and obstacles in child and adolescent mental health services in low- and middle-income countries: a review of the literature

Dutsadee Juengsiragulwit

ABSTRACT

Lower-income, less developed countries have few child and adolescent mental health professionals and a low availability of paediatric community mental health care. Child mental health professionals in low- and middle-income countries (LMICs) must therefore balance comprehensive tertiary care for the minority and provision of child and adolescent mental health services (CAMHS) within primary health care to serve the majority. This review aimed to identify the obstacles to, and opportunities for, providing CAMHS in LMICs. Articles from PsychInfo and PubMed, published up to November 2011, were retrieved using the search terms “child and adolescent”, “mental health services”, “child psychiatry”, “low- and middle-income countries”, “low-income countries” and “developing countries”. Articles were then retrieved from PubMed alone, using these search terms plus the individual country names of 154 LMICs. Fifty-four articles were retrieved from PsychInfo and 632 from PubMed. Searching PubMed with 154 LMIC names retrieved seven related articles. Inclusion criteria were (i) articles relating to CAMHS or child psychiatric services; (ii) subjects included in the articles were inhabitants of LMICs or developing countries; (iii) articles reported in English. After removal of duplicates, 22 articles remained. The contents of these articles were categorized and analysed by use of the six domains of the *World Health Organization assessment instrument for mental health systems* (WHO-AIMS), a tool developed to collect information on available resources within mental health systems. The provision of CAMHS in LMICs clearly needs a specific strategy to maximize the potential of limited resources. Mental health-policy and awareness campaigns are powerful measures to drive CAMHS. Training in CAMH for primary health-care professionals, and integration of CAMHS into existing primary health-care services, is essential in resource-constrained settings. A wide gap in research into CAMHS still needs to be filled. To overcome these challenges, the child mental health professional’s role in LMICs must encompass both clinical and public-health-related activities.

Key words: child and adolescent, child psychiatry, low- and middle-income countries, mental health services

BACKGROUND

Since 1977, the World Health Organization (WHO) has recommended promotion of child and adolescent mental health (CAMH). However, according to the *Atlas: child and adolescent mental health services*, published by WHO in 2005,¹ countries with the largest proportion of children and

adolescents are those that most lack specific CAMH policies, and lower-income, less developed countries have the fewest child and adolescent psychiatrists and other mental health professionals and the lowest availability of community mental health care. Because more than 50% of nations globally are categorized as low- and middle-income countries (LMICs), this is one of the most prevalent problems worldwide.

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Several overviews of child and adolescent mental health services (CAMHS) in LMICs have highlighted the shortage of CAMH professionals, and low accessibility and availability of CAMHS.²⁻⁵ The few child psychiatrists in these countries also generally act as team leaders within the CAMHS and are faced with the difficult balance of providing comprehensive tertiary care for the minority and CAMHS within the primary health-care setting to serve the majority. Guidance is needed on how best to allocate time between clinical practice and on administration of limited resources for provision of community service. Through a search of practice reported in the published literature, this review aimed to identify the obstacles to, and opportunities for, providing CAMHS in LMICs.

METHODOLOGY

Articles published up to November 2011 were retrieved from two search engines, PsychInfo and PubMed, using the search phrases: (i) “child and adolescent mental health service”/“child psychiatry” and (ii) “low-and middle-income countries”/“low-income countries”/“developing countries” in the title and abstract fields. Articles were then retrieved from PubMed alone, using these search terms plus the individual country names of 154 LMICs as defined by the World Bank 2011 classification.⁶ All articles were imported to EndNote for criteria analysis. Inclusion criteria were: (i) articles relating to CAMHS or child psychiatric service; (ii) subjects included in the articles were inhabitants of LMICs or developing countries; (iii) articles reported in English. Exclusion criteria were: (i) unrelated articles, i.e. on adult mental health service, community mental health, interventional and other psychosocial issues not related to CAMHS; (ii) articles with subjects in developed or high-income countries, e.g. refugees or immigrants; (iii) commentaries and editorials. The full text of the articles meeting the criteria was retrieved, and content analysis and data extraction was carried out. The results were categorized to six domains according to the *World Health Organization assessment instrument for mental health systems* (WHO-AIMS) Version 2.2, 2005,⁷ which is a tool developed to collect information on available resources within mental health systems. The six domains are (i) policy and legislative frameworks; (ii) mental health services; (iii) mental health in primary care; (iv) human resources; (v) public education and links with other sectors; and (vi) monitoring and research.

RESULTS

A total of 54 articles were retrieved from PsychInfo and 632 articles from PubMed. Searching PubMed with the names of 154 LMICs retrieved seven related articles. After abstract screening, 21 and 31 relevant articles were identified in the PsychInfo and PubMed results, respectively. Removal of duplicates reduced the total number by 13. The remaining 39 full-text articles were assessed and 22 met the eligibility criteria.^{2,3,5,8-10,13,14,16-29} For simplicity of synthesizing the results, one review article citing three relevant studies was considered as one article. A summary of these 22 articles is presented in Table 1.

Obstacles to providing child and adolescent mental health services in low- and middle-income countries

Domain 1: Policy and legislative frameworks

Mental health policy refers to an organized set of values, principles and objectives to improve mental health and reduce the burden of mental health disorders in a population.⁷ The *Atlas: child and adolescent mental health resources*, published by WHO in 2005,¹ reported a survey of information on countries worldwide; 192 countries were contacted and 66 responded. Of the responding countries, fewer than one third had an institutional or governmental entity that had clear responsibility for CAMHS.³⁰ A 2010 overview of policy and legislative frameworks in four African countries – Ghana, South Africa, Uganda and Zambia – found that two had published or drafted policies but none had a recent national mental health plan to support implementation of CAMHS.¹⁶ Current draft or new legislation in these countries addressed none or only a few of the six provisions in the WHO legislation checklist for the protection of minors, e.g. a recommendation for separate mental health facilities for children and adults in Ghana and a recommendation for provision of age-appropriate services in South Africa.²⁰

Domain 2: Mental health service

The challenge of poorly developed CAMHS in LMICs has been described for more than 40 years.^{3,5,8-10} Despite this long-standing recognition, the gap between needs and the resources provided remains large.² For example, in a cross-sectional study of children and adolescents in a low-income urban area of Brazil over one year, only 14% of the children with mental health problems could access treatment.¹⁷ Challenges in closing this treatment gap include: difficulty in accessing and using services, owing to low socioeconomic status;^{8,10} stigma associated with mental disorder;⁵ urban-based specialist provision of CAMHS in countries where most of the population is concentrated in rural areas; and few inpatient beds allocated for CAMH care.¹⁶ In addition, CAMHS are inappropriately integrated with adult mental health services in many LMICs.¹³

Domain 3: Mental health in primary care

Overloaded services, shortage of funds and personnel, and underrecognition of the importance of CAMH can lead to low motivation for primary health-care workers to provide CAMHS.²¹ Child psychiatrists in LMICs are faced with the dilemma of choosing between developing services similar to those in high-income countries and improving provision of CAMHS in primary care.²⁰

Domain 4: Human resources

Shortage of mental health professionals is a major challenge for LMICs.^{5,27}

Table 1: Summary table of the literature on child and adolescent mental health service in low-and-middle income countries

Reference number	Author	Study design	Year; location	Opportunities or suggestions	Obstacles or challenges
8	Benjet et al.	Adolescent mental health survey	2009; Mexico	<ul style="list-style-type: none"> Adolescents from families with the lowest monthly income had lower odds of substance-use disorders. The level of education in Mexico has risen. 	<ul style="list-style-type: none"> 1 in 11, 1 in 5 and 1 in 10 of adolescents had experienced a severe, moderate or mild mental health disorder respectively, of whom only 13.7% had received treatment. A low level of parental education (primary school or less) was associated with lower odds of adolescents receiving treatment. There was a lack of use of general practitioners or paediatricians, who are key sources of care before receiving more specialized resources.
9	Dogra et al.	Case-study	2005; India	<ul style="list-style-type: none"> Feedback on CAMHS collaborative United Kingdom of Great Britain and Northern Ireland (UK)/India training course for medical students and non-medical and non-mental health staff was positive. 	<ul style="list-style-type: none"> Considerable support would be needed for the impact of such training to have organizational or long-term impacts.
10	Espinola-Nadurille et al.	Overview of country data	2010; Mexico	<ul style="list-style-type: none"> Mexico is a signatory to the Universal Declaration of Human Rights (1948), the United Nations <i>Convention on the Rights of the Child</i> (1989), the <i>Caracas Declaration of Solidarity</i> (1990)¹² and other human rights instruments with specific provisions regarding mental health care. Federal and state governments are therefore obliged to provide adequate CAMHS. A national CAMH plan should be integrated with existing national health and mental health plans, and it should clearly assign responsibilities and areas of accountability within government. 	<ul style="list-style-type: none"> CAMHS in Mexico are delivered through an underfunded, under-resourced and uncoordinated network of institutional providers isolated from the larger health-care system. There is poor access to service because 40% have no insurance. Most CAMHS were provided by specialists, with little care from non-specialist providers.
13	Fisher and Cabral de Mello	Application of WHO 4S-Framework to findings of a systematic review of mental health problems in adolescents in resource-constrained settings	2011; 33 resource-constrained countries	<ul style="list-style-type: none"> CAMH care should be integrated into the communities in which adolescents live, the institutions they attend and the organizations in which they participate, using cross-sectoral strategies. 	<ul style="list-style-type: none"> There is an absence of evidence on effective CAMH interventions in resource-constrained settings.

Reference number	Author	Study design	Year; location	Opportunities or suggestions	Obstacles or challenges
14	Hoven et al.	Cross-sectional community-based design	2008; 9 countries at differing levels of economic development (Armenia, Azerbaijan, Brazil, China, Egypt, Georgia, Israel, the Russian Federation and Uganda)	<ul style="list-style-type: none"> A pilot study assessing changes in CAMH awareness following implementation of the "awareness manual" by a WPA-WHO-IACAPAP Program Awareness Task Force¹⁵ was conducted in nine countries. The study reported a positive impact in six countries where follow-up data were collected. The next logical step would be to stimulate more permanent efforts. 	<ul style="list-style-type: none"> Widespread stigma attached to CAMH disorders impinges upon the quality of life experienced by youths suffering from such problems, and serves as a barrier to prevention and treatment efforts.
2	Kieling et al.	Literature review	2011; worldwide	<ul style="list-style-type: none"> Sufficient evidence exists for establishing CAMHS in LMICs. CAMH research in LMICs is needed. Early intervention/prevention helps avoid adult mental health problems. 	<ul style="list-style-type: none"> Mental health problems affect 10–20% of children and adolescents worldwide and account for a large portion of the global burden of disease. Only 10% of CAMH trials come from LMICs, where 90% of children reside. Development of services is hindered by lack of government policy, inadequate funding and a dearth of trained clinicians.
16	Kleintjes et al.	Analysis of quantitative and qualitative data	2010; Ghana, Uganda, South Africa, Zambia	<ul style="list-style-type: none"> All four countries have a national mental health policy. Mental health needs of children and adolescents were specifically mentioned only in the mental health policies of South Africa (1997) and Uganda (draft, 2000). The South Africa policy recommends key strategies, such as a safe and supportive environment, information, skill-building, counselling and access to appropriate health services. 	<ul style="list-style-type: none"> CAMH-related legislation, policies, services, programmes and human resources are scarce. There is a low percentage of CAMH inpatient beds in all four countries. There is a lack of training of allied workers, e.g. teachers, in identification, management or referral of CAMH cases.
17	Lund et al.	Model development	2009; South Africa	<ul style="list-style-type: none"> The spreadsheet model presented can be used as an advocacy tool to engage with policy-makers to design CAMHS, and can be adapted for use in other countries. 	<ul style="list-style-type: none"> There is a substantial shortfall between current service provision in South Africa and the modelled resources required.

Reference number	Author	Study design	Year; location	Opportunities or suggestions	Obstacles or challenges
18	McKelvey et al.	Review article	1997; Viet Nam	<ul style="list-style-type: none"> • A training course targeted at recognition and treatment of CAMH disorders by both western and traditional health workers in primary health care. • Joint collaboration between psychiatrists from developed and developing countries. 	<ul style="list-style-type: none"> • Transportation limits accessibility to hospitals where the only psychiatrists practise. • Most Vietnamese individuals rely heavily on traditional healers. • Resources for prevention and treatment of CAMH disorders are extremely limited.
19	Minde	Annotation	1976; developing countries	<ul style="list-style-type: none"> • Children with general behavioural disorders, learning difficulties and antisocial behaviour should and can be treated by paramedical personnel in the community. • This requires knowledge of child development and specific behavioural problems to be incorporated into the training of medical and public-health assistants, as well as teachers. 	<ul style="list-style-type: none"> • There is low awareness of CAMH needs and general inadequacy of service. • Help is sought from indigenous healers before CAMHS.
20	Minde and Nikapota	Review article	1993; developing countries	<ul style="list-style-type: none"> • Child psychiatrists in developing countries must be trained to function within not only a medical model but also a public-health model. 	<ul style="list-style-type: none"> • Conflict between developing comparable services to those in the developed world and focusing on provision of primary mental health care.
3	Morris et al.	Analysis of WHO-AIMS data ⁷	2011; 42 LMICs	<ul style="list-style-type: none"> • Collaboration between education and mental health sectors could promote prevention and include selective interventions with groups of children and adolescents with a higher risk for emotional or behavioural health problems, in addition to diagnosis and treatment of individuals with specific CAMH needs. 	<ul style="list-style-type: none"> • The median 1-year-treated prevalence of CAMH issues is 159:100 000 population, compared with 664:100 000 in adults. • Minimal child and adolescent training exists for mental health professionals. • A limited numbers of schools have mental health professionals (1%) with limited services; 63% reported 1–20% of schools provide prevention and promotion activities for mental health.
21	Nikapota	Review article	1991; developing countries	<ul style="list-style-type: none"> • Integration of CAMH into existing network such as the Integrated Management of Childhood Illness and the Mother and Child Health Programmes might benefit both CAMH outcomes and physical outcomes. 	<ul style="list-style-type: none"> • Overloaded services, shortage of funds and personnel and underrecognition of the importance of CAMH leads to low motivation for primary health-care workers to provide CAMHS.

Reference number	Author	Study design	Year; location	Opportunities or suggestions	Obstacles or challenges
22	Omigbodun	Narrative review	2008; resource-poor countries	<p>Development of child mental health service in resource-poor countries may be supported by:</p> <ul style="list-style-type: none"> • provision of adequate advocacy tools to highlight the burden • poverty alleviation • health-awareness programmes • enforcement of legislation • regionally centred training • partnerships with professionals in developed countries. 	<ul style="list-style-type: none"> • Many CAMH problems remain invisible to policy-makers. • Absence of CAMH policies to guide services development. • Overburdened CAMH professionals. • Belief systems about mental illness that prompt the use of traditional healers.
5	Patel et al.	Literature review	2007; worldwide	<ul style="list-style-type: none"> • There are examples of successful preventive interventions in LMICs, such as an intervention to combat youth substance abuse in China. • Infant developmental stimulation had a positive effect on mental health outcomes in late adolescence. • Policies must address strengthening capacity for addressing youth mental health disorders in various settings. • Youth mental health interventions should be integrated with all existing youth programmes. • Simple youth-friendly measures are suggested, such as psychosocial support, self-help strategies, and education for mild, self-limiting disorder in non-clinical settings and community-based channels. 	<ul style="list-style-type: none"> • Most mental health needs in young people are unmet. • Key challenges include the shortage of mental health professionals, the fairly low capacity and motivation of non-specialists to provide CAMHS to youths, and the stigma associated with CAMH disorders. • There is a scarcity of mental health specialists and poor awareness of CAMH disorders and their associated stigma. • Worldwide, the clinical and public-health evidence base, particularly for childhood-onset disorders, is weak.
23	Patel et al.	Literature review	2008; LMICs	<ul style="list-style-type: none"> • Building capacity in CAMH must also focus on the detection and treatment of disorders for which the evidence base is somewhat stronger. • Capacity needs to be built across the health system, with particular foci on low-cost, universally available and accessible resources, and empowerment of families and children. 	<ul style="list-style-type: none"> • There is a vast gap between CAMH needs and the availability of CAMH resources. • There is greater variation in the pattern of disorders seen in communities than in clinics. • There is a small evidence base on CAMH, owing to insufficient skilled human resources, low awareness and low priority, high service load, greater concern for child mortality than morbidity, and journal acceptance biases against LMIC research.

Reference number	Author	Study design	Year; location	Opportunities or suggestions	Obstacles or challenges
24	Paula et al.	Cross-sectional study	2007; Brazil	<ul style="list-style-type: none"> Greater investment in improving the quality of CAMH records in public services would provide valuable data, for example to discriminate between new and returning patients, and thus aid planning of preventive and interventional activities. 	<ul style="list-style-type: none"> CAMH problems are frequent in the studied community. The public service structure is insufficient to cope with this burden of disease. The service-delivery capacity was only 14% of the estimated demand over a 1-year period.
25	Petersen et al.	Narrative review	2010; South Africa	<ul style="list-style-type: none"> Trained and supported community-based workers can produce good outcomes, and development of human resources remains key in providing CAMHS. Particular successes in early-childhood policy development and implementation relate to introduction of child-support grants and food supplementation/promotion of household food security. Evidence-based interventions exist for all three developmental phases: early childhood, middle childhood and adolescence. School-based life-skills programmes have been delivered within the education sector. 	<ul style="list-style-type: none"> There is a lack of evidence-based CAMH promotion and interventions in many areas. Policy about CAMH in middle childhood is unclear and the quality of basic general education is poor.
26	Rahman et al.	Annotation on service planning	2000; developing countries	<ul style="list-style-type: none"> Three methods of needs assessment for CAMHS are described and seven criteria for setting priorities. Models of service are outlined: community and primary health-care models; school-based mental health programmes; and public-health and preventive models. The importance of local culture and belief systems and working with the community is emphasized. 	<ul style="list-style-type: none"> Scarcity of trained community mental health professionals, who often work in isolation. Belief that CAMH problems can be managed only by highly trained specialists.
27	Syed et al.	Case-study of referrals to a new child mental health clinic	2007; Pakistan	<ul style="list-style-type: none"> Deliver CAMHS through the existing network of primary health-care services, especially for rural populations. There are potential benefits of involving faith healers in CAMHS provision. Build a network for referrers, by encouraging CAMH professionals who are currently working individually, to communicate and work together. 	<ul style="list-style-type: none"> Risk and protective factors for CAMH disorders can differ between developed and developing countries. Shortage of trained and specialist mental health professionals. Lack of collaboration.

Reference number	Author	Study design	Year; location	Opportunities or suggestions	Obstacles or challenges
28	Tan et al.	Comparative analysis of country data	2008; Hong Kong, Malaysia, Singapore	<p>In Malaysia:</p> <ul style="list-style-type: none"> efforts have been made to decentralize mental health promotion by training personnel in the existing health system, such as paediatricians and family medicine practitioners; there are ongoing mental health activities to increase public awareness of CAMH problems and promote good coping styles, particularly in schools. 	<ul style="list-style-type: none"> In Malaysia, CAMHS are still focused in urban areas and treatment is usually via one practitioner rather than via a multidisciplinary team. All three societies had a lack of access to treatment, owing to a dearth of CAMHS and child psychiatrists.
29	Tareen et al.	Cross-sectional community-based design	2009; UK and Pakistan	<ul style="list-style-type: none"> Pilot a collaborative project between a volunteer from the UK Royal College of Psychiatrists and Pakistan, to establish a CAMHS model in a rural area, including tertiary CAMHS separated from adult mental health service, promoting CAMH via classroom management and behaviour management at school. Provide public information via electronic media such as television. 	<ul style="list-style-type: none"> There is a large unmet need to train the workforce and develop services that are feasible and sustainable. Unmet treatment needs may be greatest for children with intellectual disability, epilepsy and depression.

CAMH: child and adolescent mental health; CAMHS: child and adolescent mental health services; IACAPAP: International Association for Child and Adolescent Psychiatry and Allied Professions; LMIC: low- and middle-income country; WHO: World Health Organization; WHO-AIMS: *World Health Organization assessment instrument for mental health systems*;⁷ WPA: World Psychiatric Association.

Lund and colleagues developed a spreadsheet model to calculate the human resources and costs required to improve the poor coverage of CAMHS in South Africa.¹⁷ They calculated that, per 100 000 population (of which 43 170 would be aged under 20 years), the minimum coverage of full-time staff would need to be 5.8 in primary health-care facilities; 0.6 in general hospital outpatient departments; 0.1 in general hospital inpatient facilities; 1.1 in specialist CAMHS outpatient departments; 0.6 in specialist CAMHS inpatient facilities; 0.5 in specialist CAMHS day services; and 0.8 in regional CAMHS teams. These minimum requirements were substantially less than were being provided.¹⁷ Compounding staff shortages, most mental health professionals are required to work in adult mental health services and therefore have less time for CAMHS. Low capacity and motivation for non-specialists to provide CAMHS is another key challenge for LMICs.⁵ Minimal CAMH training in primary care also means that the availability of staff who are skilled in early identification and management of uncomplicated CAMH cases is limited.^{3,16}

Domain 5: Public education and links with other sectors

Misperceptions about CAMH, and limited CAMHS awareness, is common among the public, policy-makers and also health professionals worldwide.^{5,14} This lack of awareness of CAMH problems in LMICs means that CAMH needs may be overlooked or neglected in primary care; in certain settings, this situation increases the likelihood that patients or their families will seek help from indigenous healers before accessing CAMHS.^{19,27}

Lack of coordination of CAMHS with other child-care sectors occurs among LMICs. In a study of 42 LMICs, most (63%) had only a few schools (1–20%) providing CAMH-promotion and prevention activities and only 1% of schools in these LMICs had one or more mental health professional on their staff.³ In addition, children and adolescents in LMICs tend to finish schooling earlier than their counterparts in high-income countries; thus, a large proportion of adolescents living in LMICs cannot benefit from school-based services.⁸

Domain 6: Monitoring and research

Because of resource constraints, LMICs may have poorly organized CAMH records,²⁴ as well as cases that are undetected, undocumented or lost to follow-up;²² this situation hinders the ability to evaluate services and leads to underestimates of the prevalence of CAMH disorders. The scarcity of epidemiological evidence unavoidably affects CAMH policy and planning. In particular, Patel et al. have highlighted that the “small evidence base on CAMH is due to insufficient skilled human resources, low awareness and low priority, high workload, greater concern for child mortality than morbidity, and journal acceptance biases against LMIC research”.²³ Interestingly, no published articles about the effectiveness of CAMHS provision were found in this review, which may reflect the early stage of CAMHS research in LMICs.

Opportunities for providing child and adolescent mental health services in low- and middle-income countries

Few published reports on successful strategies were found. The opportunities described below were synthesized from evidence of success and recommendations in the articles reviewed.

Domain 1: Policy and legislative frameworks

Based on their systematic review of the available evidence, in 2011 Fisher and Cabral de Mello outlined how CAMH policies, strategies and services in resource-constrained countries can be strengthened. They concluded that, in the absence of evidence for effective interventions in these settings, a broad public-policy response should encompass direct strategies for prevention, early detection, intervention and treatment; health-service and health-workforce development; social inclusion of marginalized groups of adolescents; parent, public and primary, secondary and tertiary education; and school-health policies to promote emotional well-being and prevent mental health problems.¹³

The key strategies of the South Africa CAMHS policy were provision of a safe and supportive environment, skill building, counselling, and access to appropriate health services.¹⁶ By use of their spreadsheet model to calculate the human resources and costs required to scale up CAMHS in South Africa, Lund and colleagues estimated that full and minimum CAMHS coverage would cost US\$ 21.50 and US\$ 5.99 per child or adolescent per year, respectively.¹⁷ In Sri Lanka, data collection to demonstrate the presence of treatable child mental health problems was used to persuade policy-makers to include CAMHS in primary care.²⁶

Most LMICs have ratified the United Nations *Convention on the Rights of the Child*, in which mental health is addressed from a broad perspective, from emotional well-being to the right to good-quality health care.¹¹ Nevertheless, there is no evidence of any correlation between ratification of the Convention and a country's development of CAMHS.¹ India was the second country in Asia, after the Philippines, to establish a National Commission for Children to protect children's rights. In Malaysia, a Ministry of Development of Women, Children and Family has been set up to handle children's and women's needs. The Child Act of 2001, the Woman and Girl Protection Act 1973, and the Juvenile Court Act 1974 have enhanced the statutory protection and rights of children in this country.²⁸

Domain 2: Mental health service

In certain resource-poor locations, a large proportion of CAMH care is provided outside the health sector, such as in education, juvenile justice or child welfare services.^{8,10,24} In an overview of establishing a CAMHS in Pakistan, Syed et al. noted the potential for delivery of CAMHS via the existing primary-care system, especially in rural areas, and the need

to encourage CAMH professionals who work individually to form a network for referrers; they also noted the potential benefits of involving faith healers in, rather than alienating them from, CAMHS provision.²⁷ Paula et al. noted that greater investment in improving patient records in CAMHS could allow more efficient use of limited resources by, for example, allowing cases to be identified as new or returning.²⁴

A review of CAMH in South Africa cited evidence-based community-level interventions from three relevant studies for three phases of development – early and middle childhood and adolescence.²⁵ For early childhood, one randomized controlled trial reported the effectiveness of a mother–child stimulation programme using trained community-based workers.³¹ For middle childhood, a randomized controlled trial provided evidence for the utility of a family-strengthening programme using trained community-based workers.³² With regard to adolescence, a systematic review of community-level mental health promotion that focused on life-skills education provided evidence for a positive impact on adolescents’ knowledge, attitudes and communication, although the impact on actual behaviour change was limited.³³

Collaboration between mental health and educational sectors creates opportunities to improve CAMHS. Prevention-focused activities can create healthy school environments,³⁴ and integration of mental health services into schools can allow selective interventions with groups of children and adolescents at higher risk of mental health problems, as well as diagnosis and treatment.³

Domain 3: Mental health in primary care

Several authors stressed the untapped potential of CAMHS delivery through existing paediatric or primary health-care services, especially for rural populations.^{1,21,27} Kieling and colleagues noted that integration of child mental health care with other paediatric and primary-care services, such as the Integrated Management of Childhood Illness and Mother and Child Health Programmes, might benefit both mental health outcomes and physical outcomes for children and adolescents.² In 1976, Minde noted that children with general behavioural disorders should and could be managed by appropriately trained paramedical personnel, such as community health workers and teachers.¹⁹ In their overview of CAMHS planning for developing LMICs, Rahman and colleagues noted that a model whereby mental health care was integrated into the primary-care network and supported by specialists emphasized prevention and promotion and encouraged community involvement; they also noted that such a model required changes in the roles and training of both primary-care and mental health professionals.²⁶

Domain 4: Human resources

“Task-shifting” is one method proposed to make better use of the limited numbers of trained mental health professionals in LMICs. It involves delegating certain tasks to professionals

with less training, or to non-professionals. In addition, enhanced collaboration with referring paediatricians and family physicians has been proposed. However, the efficacy and impact of these strategies remain unknown.^{3,27,28} Several authors have emphasized the need for improved training of mental health and primary-care professionals and community-based workers as key to delivering CAMHS in LMICs.^{3,25} Minde and Nikapota noted the need for training in child psychiatry in LMICs to encompass not only the clinical but also the public-health aspects of CAMHS.²⁰ Evidence from South Africa indicates that trained and supported community-based workers can produce good outcomes in CAMH.²⁵ Recommended components of training curricula include child development; interviewing children and their families; recognition of psychosocial factors; behavioural abnormalities; recognition of child psychiatric disorders; and evidence-based care strategies that will aid accurate professional interpretation of the child’s manifesting symptoms, and help the parents to effectively respond to the child’s emotional needs.^{3,9,19} In Viet Nam, McKelvey et al. noted the potential value of training courses for both conventional and traditional practitioners at the primary health-care level in targeting the recognition and treatment of CAMH disorders.¹⁸

Partnerships between psychiatrists from developed and developing countries should benefit both CAMHS and research in CAMH.^{18,29} A collaborative training and train-the-trainer course by professionals from the United Kingdom of Great Britain and Northern Ireland and from India, for medical students, non-medical and non-mental-health staff at an Indian institution was generally well received, but the authors noted that considerable support would be needed for such activities to have a sustainable effect.⁹

Domain 5: Public education and links with other sectors

In 2004, a joint taskforce of the World Psychiatric Association, World Health Organization and International Association for Child and Adolescent Psychiatry and Allied Professions (WPA-WHO-IACAPAP) created an “awareness manual” for use in child mental health-awareness campaigns.^{14,15} The manual was designed such that it could be adapted to suit local needs at the least cost. Use of the manual was piloted in students, parents and teachers in Armenia, Azerbaijan, Brazil, China, Egypt, Georgia, Israel, the Russian Federation and Uganda. In six of these countries, follow-up data were collected and showed that the campaigns had resulted in increased knowledge and understanding of CAMH in all locations, despite variation in cultures, campaign methods and the level of economic development. The results indicated that low-cost awareness campaigns can be effective, flexible and feasible and warrant refinement, expansion and further application and evaluation.¹⁴

Growing numbers of LMICs have specific education and awareness campaigns. In a survey of 42 LMICs reported by Morris et al. in 2011, 38 countries had mental health-education and awareness activities targeted at children and adolescents, and 29 countries had awareness campaigns on mental health aimed at teachers.³

Many authors in the literature surveyed emphasized the critical importance of collaboration between CAMHS and other child-care sectors such as education, child health and social welfare.^{3,8,24,27} Local women's and youth unions in Viet Nam supplement the work of primary health-care providers to provide psychosocial treatment for children and adolescents with substance-use and conduct disorders.¹⁸

Domain 6: Monitoring and research

The establishment of the WHO-AIMS in 2005 provided an important tool for service assessment.⁷ It provides essential information to strengthen mental health systems and allow monitoring of progress among countries.⁷ Periodic review of services and the community's needs before making appropriate modifications should be conducted routinely, as the needs of CAMHS evolve over time.²⁶ Rahman and colleagues discussed the three broad methods used to analyse CAMH needs – epidemiology of mental health problems and their risk factors; comparative need assessment; and corporate need analysis. The latter involves synthesis of views on the mental health needs of children from those agencies involved in their care and seems a reasonable approach in resource-poor countries.²⁶

CAMHS research in and for LMICs remains weak. The research gaps include estimates of CAMHS needs by determination of the prevalence of CAMH disorders in primary health-care settings; community-based prevalence studies; evaluations of community attitudes towards CAMH disorders; identification of parents' views on appropriate CAMHS; determination of pathways of service accessibility; development of effective CAMH screening instruments for use by non-medical personnel; and randomized controlled trials of psychosocial treatment and the cost-effectiveness of interventions in LMICs.^{2,18} Improvements to the quality of mental health-care records should be made to serve as a basis for research and particularly treatment planning in the future.²⁴

DISCUSSION

A surprising finding from the review is that the current situation of CAMHS in LMICs is quite similar to that of 40 years ago. Evidence is scarce and much of the evidence base comes from reviews of limited data or expert opinions rather than objective measures of interventions.

Regarding domain 1 of the WHO-AIMS,⁷ on policy and legislative frameworks, policy can clearly be a powerful instrument to drive CAMHS in LMICs, where it exists. CAMH legislation existed in some LMICs but this did not necessarily imply implementation. Many adults with mental health problems develop their symptoms before the age of 15 years and CAMH disorders may result in a long-lasting effect throughout life.² Appropriate advocacy must ensure that this information is shared with policy-makers, to enable greater legislative underpinning of CAMHS in LMICs.

Domains 2 and 3 of the WHO-AIMS⁷ relate to mental health service and mental health in primary care. CAMHS originated in developed countries, began at tertiary level then expanded into primary health care, to cover the majority of children.²² By applying lessons learnt from the evolution of CAMHS in high-income countries, there is an opportunity to develop CAMHS in LMICs in the opposite direction, i.e. by promoting CAMHS in primary health care. Although the work reviewed concurred that this is the best solution, there was also acknowledgement, especially in low-income countries, that the priorities of community and primary health-care personnel are usually communicable or life-threatening diseases rather than CAMHS. Training community-based workers for CAMHS may simply increase the workload of an already-stretched workforce, which may reduce cooperation with CAMHS initiatives. Nevertheless, integrating CAMHS into existing routine work in primary health care has been the most-explored option to date, and a sustained effort to integrate CAMH into the public-health system at the local level should ultimately establish sustainable service into that community.

Human resources are addressed in domain 4. The median number of psychiatrists in LMICs is 172 times less than in high-income countries and thus task-shifting is an obvious strategy to increase CAMHS human resources.⁴ Personnel in primary health care are an existing network of individuals who are familiar with the community, so in theory may be good providers of CAMHS for the child and adolescent populations. Questions about which tasks should be shifted, who should manage and oversee the task-shifting, and how to motivate other professionals to take on these responsibilities, are still unanswered.

Domain 5 focuses on public education and links with other sectors. Uniting the CAMH workforce in different sectors will create a synergistic effect, which is necessary for establishing CAMHS in resource-poor countries. In decentralized settings, local authorities have become more relevant to CAMHS provision. CAMHS will be unsustainable in any community where the local authorities do not involve all sectors. Since promoting the needs of children and adolescents often lies outside health sectors, intersectoral linkages and empowerment of non-health sectors that interact with children will enable promotion of CAMH, early detection of CAMH problems, and development of an effective service network. Strengthening the capacities of non-specialist workers, e.g. child-care workers, teachers and social workers, would be helpful in improving child mental health and well-being, especially in areas where specialists are scarce. The education sector is an important agent that should increase engagement in CAMHS.

Another barrier in LMICs is the relationship between poverty and child psychopathology, as highlighted, for example, in the Great Smoky Mountain Study in the United States of America.³⁵ In this natural longitudinal experiment, families that moved out of poverty experienced a reduction in their children's conduct and oppositional disorder but not their anxiety and depression. The findings suggest that children's symptoms, particularly

those of oppositional and deviant behaviour, were affected by economic constraints on parents' ability to devote scarce time to supervising their children.³⁵

Monitoring and research are the subject of domain 6. Sharing resources among countries to conduct a regional epidemiological survey would potentially be a cost-effective option for LMICs and regional results may be more generalizable than national data.

Child mental health professionals have a dilemma when deciding what to do first. Their training may focus on academic issues of treatment and rehabilitation in highly specialized areas and may rarely cover the skills required for administration of CAMHS. This reinforces the model whereby CAMH is seen as a tertiary-care specialty rather than an integral part of primary health care. However, developing excellent services in urban-based clinics while the majority of patients live in rural areas is not an equitable way to provide CAMHS and may lead to hospital clinics being overcrowded with patients, many of whose mental health difficulties could and should have been managed in the community. Although many child mental health professionals realize the importance of CAMHS in primary health care, resource and time constraints will limit their abilities to manage this problem. Nevertheless, it is the responsibility of mental health practitioners to convince policy-makers and funders about the nature of CAMH in child development, through the media and publication of research and surveys.³⁶

Many LMICs are non-English-speaking countries, so elimination of non-English language publications is a major limitation of this review. Researchers from these countries are likely to have more difficulties publishing their work in English, which leads to publication bias. It is likely that there is considerable information in the local languages of these researchers that could not be included in this review.

Conclusion

The provision of CAMHS in LMICs needs a specific strategy to maximize the potential of limited resources. Mental health-policy and awareness campaigns are powerful measures to drive CAMHS. Training in CAMH for primary health-care professionals, and integration of CAMHS into existing primary health-care service is required in resource-constrained settings. A wide gap in research into CAMHS still needs to be filled. To overcome these challenges, child psychiatrists in LMICs need a perspective that includes both medical and public-health-related factors, as well as an ability to seize the opportunities that exist among the many obstacles.

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HIV drug-resistance early-warning indicators and quality care in India: preliminary findings from a pilot study in Pune city

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ABSTRACT

Background: India has rapidly scaled up its programme for antiretroviral therapy (ART). There is high potential for the emergence of HIV drug resistance (HIVDR), with an increasing number of patients on ART. It is not feasible to perform testing for HIVDR using laboratory genotyping, owing to economic constraints. This study piloted World Health Organization (WHO) early-warning indicators (EWIs) for HIVDR, and quality-of-care indicators (QCIs), in four ART clinics in Pune city.

Methods: A retrospective study was conducted in 2015, among four ART clinics in Pune city, India. The data on four standardized EWIs (EWI 1: On-time pill pick-up, EWI 2: Retention of patients in ART care at 12 months after initiation, EWI 3: Pharmacy stock-out, EWI 4: Pharmacy dispensing practices) and three QCIs (QCI 1: Regularity in CD4 testing in patients taking ART, QCI 2: Percentage of patients initiating ART within 30 days of medical eligibility, QCI 3: Percentage of patients initiating ART within 30 days of initiation of anti-tuberculosis therapy) were abstracted into WHO Excel HIV data abstractor tools, from the patient records from April 2013 to March 2014.

Results: All four ART clinics met the EWI 4 target (100%) for ART dispensing practices. The target for EWIs on-time pill-pick (EWI 1 >90%) and pharmacy stock-outs (EWI 3: no stock-outs, 100%) were achieved in one clinic. None of the clinics met the EWI 2 target for retention in care at 12 months (>90%) and the overall retention was 76% (95% confidence interval: 73% to 79%). The targets for QCI 1 and QCI 2 (>90% each) were achieved in one and two clinics respectively. None of the clinics achieved the target for QCI 3 (>90%).

Conclusion: ART dispensing practices (EWI 4) were excellent in all clinics. Efforts are required to strengthen retention in care and timely pill pick-up and ensure continuity of clinic-level drug supply among the programme clinics in Pune city. The clinics should focus on regularity in testing CD4 count and timely initiation of ART.

Key words: AIDS, antiretroviral therapy (ART), early-warning indicators, HIV, HIV drug resistance (HIVDR), India

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BACKGROUND

India has an estimated population of 2.09 million individuals infected with HIV, with an adult prevalence of 0.27%.¹ The antiretroviral therapy (ART) programme in India was started in 2004 and has been scaled up rapidly to over 1200 sites across the country, with phased decentralized service delivery

to district and subdistrict health facilities. Up to March 2014, 0.768 million people living with HIV (PLHIV) were on first-line ART at 425 ART centres.² Monitoring of ART care at service sites is based on both paper (for monthly ART-centre reporting) and case-based patient monitoring electronic systems (PLHA software), where every patient visit is recorded. As the ART programme approaches universal access for all those in

need, it is critical to establish monitoring systems for treatment outcomes and other programme indicators that can provide data on the quality of ART services.

The national programme has completed a decade and it is expected that the number of patients with treatment failure will be on rise. Since the development of HIV drug resistance (HIVDR) is a paramount concern in mature ART programmes, close monitoring to limit emerging HIV drug resistance and ensure the success of first-line ART is important. HIVDR may necessitate a switch from non-nucleoside reverse transcriptase (NNRTI)-based first-line regimens to more expensive and less tolerated boosted protease inhibitor-based regimens, leading to limited drug options available in the programme and an increase in the overall cost. Owing to non-availability of routine viral load and HIVDR testing in resource-limited settings, the World Health Organization (WHO), as part of its global strategy for prevention and assessment of HIVDR, developed a set of early-warning indicators (EWIs) that assess ART clinic-, patient- and programme-related factors associated with the emergence of HIVDR.³ These indicators are based on the data that are routinely collected in patients' medical and pharmacy records, are comparatively inexpensive to collect and may alert national ART programme planners to issues that can be adjusted to minimize the emergence of HIVDR.

In order to strengthen the quality of ART services, the National AIDS Control Organization (NACO) has recommended regular monitoring of quality-of-care indicators (QCIs) in HIV care, in addition to EWIs. These include regularity in testing CD4 count in patients taking ART, the percentage of patients initiating ART within 30 days of medical eligibility, and the percentage of patients initiating ART within 30 days of initiation of anti-tuberculosis therapy (ATT).

These QCIs are deemed more important in providing data for the ART programme to improve patient care at ART sites and minimize the emergence of HIVDR. They also allow comparison across time about whether the quality of ART services improves and evolves.

This pilot study assessed four standardized HIVDR EWIs and three QCIs, at four ART programme clinics in Pune city, in order to identify potential strengths and weaknesses of the programme and improve the quality of clinical care

METHODS

Study design

This retrospective study was conducted at four government ART clinics in Pune city, in 2015, to evaluate HIVDR EWIs and QCIs, from 1 April 2013 to 31 March 2014.

All four ART clinics followed the same national and operational guidelines for management of individuals with HIV infection.^{4,5} As per the guidelines, ART was initiated at a CD4 count of ≤ 350 cells/mm³, or WHO clinical stage III and IV irrespective of CD4 count. The preferred regimen was zidovudine/lamivudine/nevirapine. The patients were provided drugs for one month and were requested to come back after a

month for a follow-up visit and to collect drugs for the next one month. The patients who were on regimens containing zidovudine, tenofovir or nevirapine were requested to come after every 15 days initially for one month, to be tested for haemoglobin, renal function tests or alanine aminotransferase, respectively. A patient-centred approach was used to promote adherence, which was assessed by pill counts. Co-trimoxazole chemoprophylaxis was given as per the national guidelines.⁴

Early-warning indicators

Four EWIs based on the WHO 2012 guidelines were considered for this study,^{6,7} and are summarized in Table 1.

Quality-of-care indicators

The three QCIs, namely regularity in testing CD4 count in patients taking ART, the percentage of patients initiating ART within 30 days of medical eligibility, and the percentage of patients initiating ART within 30 days of initiation of ATT, were considered for analysis and are summarized in Table 2.

Sampling and data abstraction:

The sample size for EWI 1, EWI 2 and EWI 4 at each ART site was calculated as per the WHO sampling method.⁶ The sample size for EWI 1 and EWI 4 was calculated based on the total number of patients alive and on ART in March 2014 and the data were abstracted for consecutive patients that came for drug pick-up. The sample size for EWI 2 and QCI 1, QCI 2 and QCI 3 was based on the number of patients newly initiated on ART during April 2012 and March 2013, and the data were abstracted from medical registers. The data for EWI 3 were abstracted for the targeted year from the pharmacy records.

Ethics statement

Approval was obtained from NACO for use of routine programmatic data for EWIs. The analysis of the routinely collected programme data was approved by the ethics committee of the National AIDS Research Institute.

RESULTS

Profiles of the study sites

Profiles of the study sites were described, to support the interpretation of the EWI and QCI results. The staff-to-patient ratio was different in the four different clinics (see Table 3). Clinic B was the first government programme ART clinic established in Pune City and also functions as a reference centre where all patients from Pune district that are failing on first-line treatment are referred for second-line ART and subsequently followed up. Clinic C was established in 2010 and the staff-to-patient ratio was better as compared to other clinics.

Table 1: WHO updated HIV drug-resistance early-warning indicators and targets (2012)

Early-warning indicator (EWI)	Target	Definition	Numerator	Denominator
EWI 1: On-time pill pick-up	Red <80%	Percentage of on-time ART drug pick-up by the patients	Number of patients who have picked up all their prescribed ART drugs at first pick-up after baseline pick-up	Number of patients who picked up ART drugs on or after the designated EWI sample start date until the sample size is reached
	Amber 80–90%			
	Green >90%			
EWI 2: Retention in ART care at 12 months	Red <75%	Percentage of patients initiating ART at the site who are retained in the care at 12 months after ART initiation	Number of patients who are alive and on ART at 12 months after initiating ART	Number of patients initiating ART who were expected to achieve 12-month outcomes within the reporting period
	Amber 75–85%			
	Green >85%			
EWI 3: Pharmacy stock-out	Red <100%	Percentage of months in a designated year in which there were no ARV drug stock-outs	Number of months in the designated year in which there were no stock-out days of any ART drug routinely used at the site	12 months
	Green 100%			
EWI 4: Pharmacy dispensing practices	Red >0%	Percentage of patients prescribed or picking up mono or dual ART	Number of individuals who have picked up a mono or dual prescribed ART drug	Number of patients who picked up ART drugs on or after the designated EWI sample start date until the sample size is reached
	Green 0%			

ART: antiretroviral therapy.

Table 2: Quality-of-care indicators in ART clinics in Pune, India

Quality-of-care indicator (QCI)	Target	Definition	Numerator	Denominator
QCI 1	Target: Good: >90% Poor: <90%	Percentage of patients on ART care undergoing 6-monthly CD4 tests	Number of patients who underwent CD4 count at 6-monthly interval in ART care	Total number of patients who are enrolled in ART care and currently on treatment
QCI 2	Target: Good: >90% Medium: 80–90% Poor: <80%	Percentage of patients initiating ART within 30 days of medical eligibility in the designated year	Number of patients who received ART within 30 days of their medical eligibility in the designated year	Total number of patients eligible for ART initiation
QCI 3	Target: Good: >90% Medium: 80–90% Poor: <80%	Percentage of patients initiating ART within 30 days of initiation of ATT	Number of patients starting ART within 30 days of initiation of ATT	Total number of patients starting ART who have initiated ATT

ART: antiretroviral therapy; ATT: anti-tuberculosis therapy.

Table 3: Profile of four ART clinics in Pune, India

Clinic	Year of clinic establishment	Total number of patient in active care up to March 2014	Total number of patients alive and on ART up to March 2014	Total number of patients registered for ART in April 2013 to March 2014	Average number of ART clinic staff (doctor, nurse, counsellor, laboratory technician and pharmacist in April 2013 to March 14
Clinic A	2009	3362	2737	1319	6
Clinic B	2005	15462	6518	2795	9
Clinic C	2010	2979	2706	672	9
Clinic D	2008	6098	5286	1490	10

ART: antiretroviral therapy.

ART clinic	EWI 1: On-time pill pick-up, % (number of patients)	EWI 2: Retention in ART care at 12 months, % (number of patients)	EWI 3: Pharmacy stock-out, % of months with no pharmacy stock-outs (12 months)	EWI 4: Pharmacy dispensing practices, % of patients with mono or dual therapy (number of patients)
	Target: Red: <80% Amber: 80–90% Green: >90%	Target: Red: <75% Amber: 75–85% Green: >85%	Target: Red: <100% Green: 100%	Target: Red: >0% Green: 0%
Clinic A	84 (201)	82 (187)	83	0 (203)
Clinic B	77 (216)	67 (232)	42	0 (224)
Clinic C	94 (200)	83 (160)	100	0 (201)
Clinic D	81 (216)	74 (190)	92	0 (217)

ART: antiretroviral therapy; EWI: early-warning indicator.

Early-warning indicators in adults

The data on four adult EWIs from four ART clinics in Pune are summarized in Table 4.

EWI 1: On-time pill pick-up

Clinic C met the target for on-time pill pick-up (>90%) and clinics A and D reached near target (80–90%) with 84% (95% confidence interval [CI]: 79% to 89%) and 81% (95% CI: 76% to 86%) respectively.

EWI 2: Retention in ART care at 12 months after initiation

No clinic met the target (>85%) for retention in care at 12 months. Clinics A and C reached near target (75–85%). The overall retention in all four clinics was 76% (95% CI: 73% to 79%). Some of the significant causes of attrition among those who could not be retained at one year were loss to follow-up 39% (95% CI: 32% to 45%), deaths 38% (95% CI: 31% to 45%), and self-stopping 16% (95% CI: 11% to 21%). The overall percentage of patients who were initiated on second-line treatment was 1.6% (95% CI: 0.73% to 2.46%).

EWI 3: Pharmacy stock-out

Clinic C had sufficient pharmacy stock for the designated year, while Clinics A, B and D had pharmacy stock-outs.

EWI 4: Pharmacy dispensing practices

All four sites met the target of 100%, and appropriate initial ART regimens were prescribed according to national ART guidelines. No patient at any site received mono or dual therapy.

Quality-of-care indicators in adults

QCI 1: Regularity in CD4 testing in patients taking ART

Clinic C reached the target (>90%). Clinic A had good performance at month 6 but did not reach the target at months 12 and 24. Clinics B and D did not reach the target for regularity of testing CD4 count at months 6, 12 and 24 (see Fig. 1).

QCI 2: Percentage of patients initiating ART within 30 days of medical eligibility

The target was achieved by Clinics B and D but was not achieved in Clinic A (78.6% [95% CI: 72.8% to 84.3%]) and Clinic C (70.3% [95% CI: 63.3% to 77.3%]) (see Fig. 2).

QCI 3: Percentage of patients initiating ART within 30 days of initiation of ATT

The target was not achieved by any of the clinics (see Fig. 2). Considering the operational guidelines for ART initiation between 2 weeks and 2 months after initiation of ATT, Clinic B (90.6% [95% CI: 82.7% to 98.4%]) and Clinic D (94.8% [95% CI: 89.1% to 100.5%]) achieved this target.

DISCUSSION

As per the recommendations of operational guidelines for ART services,⁵ ART-preparedness counselling was carried out in 2–3 sessions in the ART clinics while the patients had their clinical and laboratory screening. The clinic counsellors informed the patients that the treatment was lifelong. This was further stressed on the adherence counselling, which was subsequently reiterated at each monthly clinic visit. The study results showed that the target for EWI 1 (on-time pill pick-up, >90%) was not achieved in three of the four ART clinics, in spite of these counselling sessions, which indicates the additional effort required to increase adherence and minimize visits missed by patients. The pill counts and pharmacy records also need to be appropriate so that patients can come in time before their supply

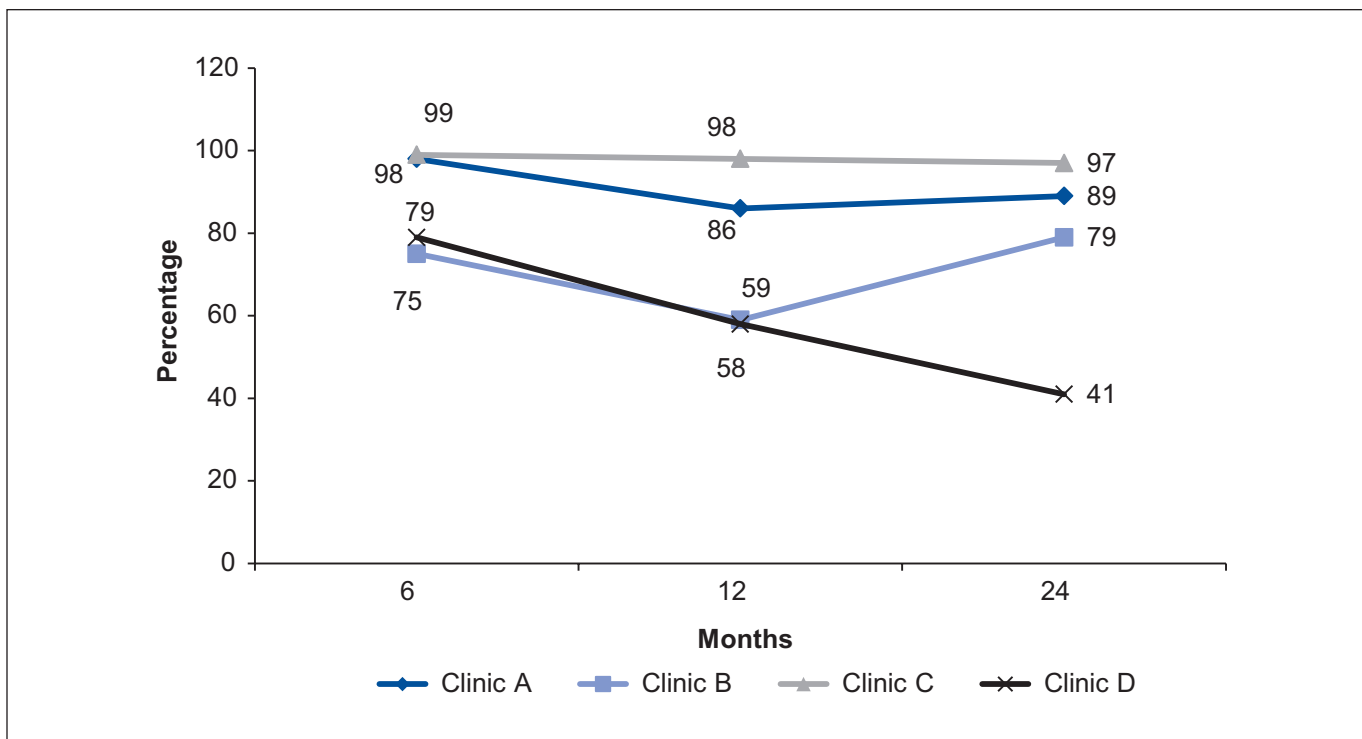


Figure 1: QCI 1: Regularity in CD4 testing among adult patients taking ART, in four ART clinics in Pune, India

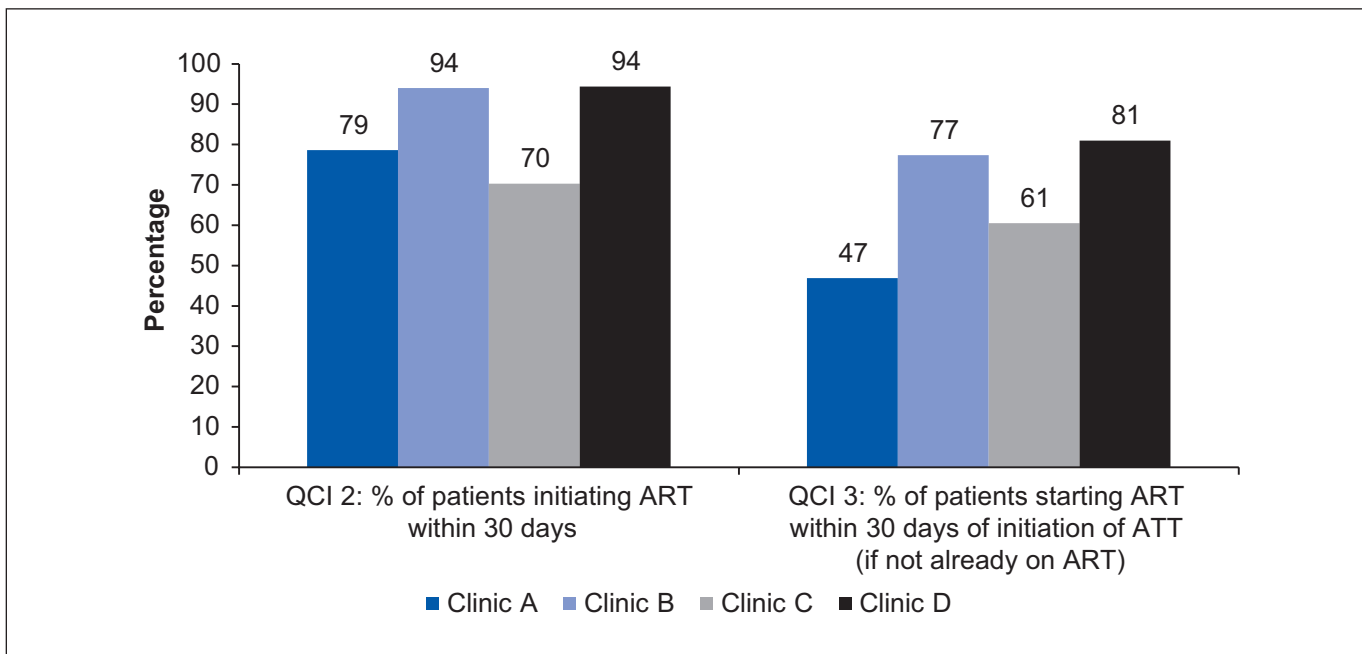


Figure 2: QCIs 2 and 3 in adults in four ART clinics in Pune, India

of pills runs out. A study has reported that picking up ART in time has been shown to be associated with viral suppression.⁸ A report from the Caribbean recommended that health-care services that deliver ART should have supportive mechanisms in place to promote adequate adherence and should proactively trace clients who fail to return for scheduled visits.⁹ A separate study should be conducted in India to find out the various

causes of delay for on-time pill pick-up, so that counselling can be strengthened to avoid treatment interruptions. This will help in increasing viral suppression at population level and, in turn, avoid development of drug resistance. Approaches like the use of mobile phones for pill pick-up reminders can be implemented to increase the adherence.

None of the ART clinics in the study achieved the target (>90%) for retention in care. The main reasons for attrition at the end of one year were loss to follow-up and death. The average retention rate at 12 months was lower as compared to a report from 70 low- and middle-income countries in 2008, where it was 79.9% globally and 80.3% in east, south, and south-east Asia.^{10,11} It was slightly lower than reported from urban ART sites in Cameroon (77.8%)¹² and similar to those in a report from 33 cohorts comprising 74 192 patients from 13 sub-Saharan countries (75.0%).¹³ If the national programme moves towards adopting WHO guidelines of increasing the CD4 count for treatment initiation to 500 cells/mm³, it becomes even more crucial to retain patients in the treatment, considering the limited availability of second-line drugs in the programme.¹⁴ The high rate of discontinuity in drug supply in three of the four clinics was an important concern. The drug stock-outs may increase treatment interruption, loss to follow-up and delay in drug pick-up. A risk of developing HIVDR remains, even though alternative therapeutic options are provided during stock-outs. It is important for the programme managers to sort out the issues related to supply management and provide continuous ART drug stock in all the ART clinics. The option of decentralization of drug procurement may be considered, and additional staff could be provided for monitoring the continuity of drug supply. The systems for calculating drug requirements and the time required for procurement and distribution must be prioritized to prevent ART drug stock-outs. Stock-outs in ART supply have also been reported in other countries.^{15,16}

The present study showed that good dispensing practices (EWI 4) are performed in all the ART clinics in the city, which is similar to the results from 35 clinics in the United Republic of Tanzania;¹⁷ this was probably due to the training of clinicians by the national programme and the ongoing supervision by the nodal officers of the clinics.

In Clinic B, suboptimal performance was observed in three EWIs, though this was the first of the four clinics to be established. This clinic functions as an ART reference centre and the number of staff should be increased, considering the patient burden, which will be important in achieving the targets.

The QCIs are being introduced in the programme to monitor the clinical care provided to patients. The target for overall regularity in CD4 testing was achieved in one clinic over the period of 2 years and irregularities were observed in the remaining three clinics at either 6, 12 or 24 months. This could be due to high patient burden, missed visits or an inadequate number or increased turnover of phlebotomy staff. In a country like India, where assay of viral load is not a part of routine monitoring, and targeted assay of viral load is performed to detect treatment failure, this QCI plays an important role for detecting immunological failure, for performing assays of viral load and for switching patients on second-line treatment, even though the CD4 marker is associated with delayed detection of ART failure and development of HIVDR.¹⁸ The clinics should strengthen the mechanism for regular listing of patients who are due for CD4 testing, and tracking of patients who are missed for CD4 testing, by adhering to the operational guidelines. This will increase the regularity in CD4 testing and monitoring of ART over the long term. The laboratory managers in the

programme should ensure timely supply of reagents for CD4 assays, so that no clinic faces a shortage, and regularity in CD4 testing can be maintained.

Timely initiation of ART benefits patients infected with HIV, by reducing their morbidity and mortality. In the present study, the target for the percentage of patients initiating ART within 30 days of medical eligibility (QCI 2) was achieved by two of the four clinics. The common reasons for delay in treatment initiation beyond 30 days include delay in laboratory investigations, lack of patient preparedness for ART initiation, co-existing tuberculosis (TB) infection and patients not approaching the clinics in time, because of their own problems.⁵ In a report from two public clinics in Malawi, the duration of the pre-ART period was found to be the most significant predictor of starting ART among eligible patients. In the Malawi study, patients who were immediately eligible for ART at initial registration had lower odds of initiating treatment than patients who spent 1–3 months in pre-ART care. The authors concluded that better understanding of the motivation for retention in pre-ART care may reduce attrition along the treatment cascade.¹⁹ A study from southern India on predictors of delayed ART initiation observed that diagnosis of TB, being homeless, lower CD4 count, longer duration of pre-ART care, being widowed and belonging to a disadvantaged community were associated with delayed initiation of ART.²⁰ The report recommended implementing targeted interventions for patients at high risk of programme attrition.

The target for the percentage of patients initiating ART within 30 days of initiation of ATT (QCI 3) was not achieved by any of the four clinics in this study. However, two clinics could achieve the target for starting ART within 60 days after initiation of ATT.

TB remains an important cause of death among patients infected with HIV. The operational guidelines recommend that ART should be started between 2 weeks and 2 months after initiation of ATT, as soon as the TB treatment is tolerated. A study from northern India on early versus delayed initiation of ART for Indian individuals infected with HIV and on ATT stated that early initiation of highly-active antiretroviral therapy (HAART) for patients with HIV and TB significantly decreases the incidence of HIV disease progression and has good tolerability.²¹ The ART clinics should strengthen their mechanism for tracking TB patients infected with HIV who are referred to TB centres, and proactively retain them under care for early initiation of ART. This will improve the quality of care provided to the patients in the national programme who are co-infected with HIV and TB.

The study has limitations. It was not possible to include EWI 5, on viral suppression at 12 months, as this was a retrospective study and routine testing of viral load is not recommended in the programme. The data on HIVDR could not be used to predict the association of each EWI with viral load. The study sites were limited and hence the findings are not representative of ART clinics nationally. Data on EWIs for paediatric groups were not included. The data were abstracted by a trained team but were not validated. The date of starting ATT was not

obtained for all patients and so the date of diagnosis of TB was used as a proxy, which may overestimate the results.

CONCLUSIONS

The study has shown good ART dispensing practices in all the four clinics studied but retention in care, on-time pill pick-up, drug supply, and the number of days required for ART initiation after eligibility did not meet the desired target. This survey can be used by programme managers to identify areas of weakness and take measures accordingly. The quality of patient care will improve by integrating EWI and QCI into routine monitoring of ART clinics in the national programme.

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Lessons for addressing noncommunicable diseases within a primary health-care system from the Ballabgarh project, India

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ABSTRACT

Background: Most patients with noncommunicable diseases (NCDs) can be managed appropriately at the primary care level, using a simplified standard protocol supported by low-cost drugs. The primary care response to common NCDs is often unstructured and inadequate in low- and middle-income countries. This study assessed the feasibility of integration of NCD prevention and control within the primary health-care system of India.

Methods: This study was done among 12 subcentres, 2 primary health centres (PHCs) and one subdistrict hospital in a block in north India. All 28 multipurpose health workers of these subcentres underwent 3-day training for delivering the package of NCD interventions as a part of their routine functioning. A time–motion study was conducted before and after this, to assess the workload on a sample of the workers with and without the NCD work. Screening for risk assessment was done at domiciliary level as well as at health-facility level (opportunistic screening), and the cost was estimated based on standard costing procedures. Individuals who screened positive were investigated with electrocardiography and fasting blood sugar. PHCs were strengthened with provision of essential medicines and technologies.

Results: After training, 6% of the time of workers ($n = 7$) was spent in the NCD-related activities, and introduction of NCD activities did not impact the coverage of other major national health programmes. Loss during referral of “at-risk” subjects (37.5% from home to subcentre and 33% from subcentre to PHC) resulted in screening efficiency being lowest at domiciliary level (1.3 cases of NCDs identified per 1000 screened). In comparison to domiciliary screening (₹21 830.6; US\$ 363.8 per case identified), opportunistic screening at subdistrict level (₹794.6; US\$ 13.2) was 27.5 times and opportunistic screening at PHC (₹1457.5; US\$ 24.3) was 15.0 times lower. There was significant utilization of NCD services provided at PHCs, including counselling.

Conclusion: Opportunistic screening appears to be feasible and a cost-effective strategy for risk screening. It is possible to integrate NCD prevention and control into primary health care in India.

Key words: cost, health workers, noncommunicable disease, primary health care, risk assessment

BACKGROUND

Noncommunicable diseases (NCDs), which were once considered “diseases of affluence”, have now invaded low- and middle-income countries as well. In 2008, roughly four out of five NCD deaths occurred in low- and middle-income countries,

up sharply from just under 40% in 1990.¹ Adding urgency to the NCD challenge is the fact that the number of people living with NCDs will increase substantially in the coming decades. The cost of an acute event or chronic care has been shown to place a heavy burden on individual households, which may result in catastrophic expenditures. A high proportion of

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patients do not purchase prescribed medicines because they cannot afford them. NCDs can change the spending patterns of households dramatically and result in significant reduction in spending on food and education.^{2,3} Low- and middle-income countries are characterized by health-care costs being borne by patients themselves and by limited coverage of health insurance schemes, in terms of population as well as services covered.

Primary health care offers a way to improve fairness in access to health care, and efficiency in the way resources are used.⁴ It is now well recognized that the increasing burden of NCDs in India and the world is best addressed by a primary health-care approach.⁵ Primary-health-care facilities are patients' first point of contact with health services and hence the most appropriate places for patient screening and early disease detection, continuous care provision for uncomplicated patients, and referral of patients to specialists. Most patients with NCDs do not require specialized care and can be managed appropriately at the primary care level, using simplified standard protocols supported by low-cost drugs and with links to higher levels of care for people who need them. Managing NCDs (as is true for other diseases as well) at primary care level has several additional advantages: it provides a technically equivalent level of care; it is provided in a setting that is closer to the patient both physically and socioculturally; it imposes lower cost to both the patient and health system; and follow-up for monitoring compliance and control can be more effectively done.

The primary care response to common NCDs in most low- and middle-income countries is unstructured and inadequate.⁶ There is an urgent need for a framework for use and adaptation by countries to improve the delivery of interventions for patients with chronic NCDs by primary care providers.⁶ This calls for operational research into integrating NCDs into the primary health-care system of low- and middle-income countries.⁷ One of the objectives of the *WHO Global Action Plan for the Prevention and Control of NCDs 2013–2020* is to use people-centred primary health care and universal health coverage to strengthen and orient health systems to address the prevention and control of NCDs and their underlying social determinants.⁸

An operational research study was undertaken to define and validate packages of services and tools for the prevention and management of NCDs within the primary health-care system of India. As a part of the Indian Council of Medical Research Task Force study, the following questions were identified for answering, based on the need for inputs into the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Diseases including Stroke (NPCDCS).⁹

1. Does the current workload of multipurpose health workers (MPHWs) allow the additional introduction of NCD programme-related work or will it affect the performance of other programmes?
2. Which strategy should be chosen for screening for high-risk individuals – domiciliary or opportunistic screening at primary and secondary health facilities?
3. What would be the likely utilization of different facilities like counselling, blood glucose, electrocardiography (ECG) and medicines at the primary health-care level?

Overview of the primary health-care system in India

The lowermost tier of the publicly funded formal primary health-care system comprises MPHWS. One team of male and female MPHWS caters to a population of about 5000–7000 distributed over 2–4 villages, which together form the population under a subcentre. Six subcentres come under a primary health centre (PHC), which serves a population of 30 000–40 000. One male and one female health assistant supervise the work of MPHWS at PHC level. At the PHC, there is usually one medical officer who provides clinical care, as well as administering and supervising the community-level work. There are additional nurses who look after the ward, primarily for childbirth. At the next higher level is the community health centre, which is usually 30 bedded and provides specialist service in medicine, paediatrics, obstetrics, surgery and anaesthesia. It serves as the first referral unit and has an operating theatre for routine and emergency services. These are generally for a population of 120 000–150 000. Above this is usually the district hospital, which has around 200 beds and has other specialists like orthopaedics, ophthalmology, etc. In many places, there are also subdistrict hospitals, which fall somewhere in between these two levels. NPCDCS currently focuses mainly in strengthening district hospitals.

METHODS

Study setting

This study was done in the health facilities under the Centre for Community Medicine of the All India Institute of Medical Sciences, New Delhi. This is located in Ballabgarh Block of Haryana State, about 30 km from the institute. It consists of 12 subcentres, two PHCs covering a population of about 88 000 in 28 villages in 2007, and one civil hospital (subdistrict hospital). The study site has been described in detail elsewhere.¹⁰ The fieldwork for this study was carried out from August 2007 to December 2009.

Ethics

The study was approved by the All India Institute of Medical Sciences Ethics Committee. The study was implemented as a strengthening of existing services of the PHCs.

Training

All MPHWS and their supervisors ($n=28$) underwent a 3-day orientation/training programme held during February 2008. They were made aware of NCDs, their link to changing lifestyles and the need to tackle their increasing burden. They were trained for NCD risk assessment (techniques for asking questions, as well as skills for anthropometry) and other activities (health education/advising for tobacco cessation, dietary modification and physical activity). Each didactic session was followed by hands-on exercises on themselves and their co-trainees. In addition to MPHWS, six research staff were also trained.

Risk-assessment procedure

A NCD risk-assessment tool was designed, based on data from the previous Indian Council of Medical Research multicentre risk-factor survey.¹¹ In keeping with the requirement for use by MPHWs, it was a three-stage tool. At the first stage (domiciliary), there was a 10-item questionnaire covering age, tobacco use, alcohol use, physical activity, diet, waist circumference and family history of NCDs. The total score possible was 20 and individuals with a score of more than 8 were asked to report to the subcentre for the second stage, where blood pressure, height and weight (for body mass index [BMI]) were measured. If the score was then greater than 12, the subject was referred to the PHC for ECG and testing of fasting blood sugar. If, at the PHC, any of these test results were abnormal, the patient was registered in the NCD clinic at the PHC and started on treatment by a doctor, based on standard treatment protocols developed for these diseases. They were additionally referred to the Civil Hospital Ballabgarh for serum cholesterol measurement and a physician consultation, if needed.

Work schedule

After the training, up to the end of the project, the health workers were expected to conduct NCD risk assessments during their routine schedule; identify and refer individual with symptoms suggestive of NCDs; provide advice for lifestyle modification; and follow up patients with disease, for compliance and monitoring. Individual risk-assessment cards with health messages were developed, to be retained by the individuals. The monthly reporting forms were modified to add a section for NCDs, which would list the activities conducted by the health worker in a given month, such as the number of risk assessments done and individuals identified with an assessed risk score of more than 8.

Comparison of screening strategies

Two approaches for screening for NCDs were tested in the study. These are summarized in Figure 1.

Domiciliary screening

NCD risk assessment of all individuals aged over 20 years available at the time of home visit was carried out by two trained research workers in two villages and was completed between January and March 2009. It was a three-stage process as described above. The cut-off age of 20 years was decided by the advisory committee, as a good trade-off between workload and the need to catch risks early.

Opportunistic screening

In this approach, four of the remaining trained research staff conducted NCD risk assessment of all patients older than 20 years attending the outpatient services of the two PHCs and the Civil Hospital Ballabgarh (where this was restricted to those older than 40 years, owing to the heavy workload of patients). In this approach, the first two stages were combined and individuals were referred to ECG or fasting blood sugar testing if they were above the cut-off value of 12. This screening continued at the health facilities, for at least 6 months, between May 2008 and April 2009. Subjects referred from PHCs or the field were not subjected to this screening.

Health-facility strengthening

The primary care facilities were strengthened by training of medical officers on the use of a standard simplified protocol for common NCDs (hypertension, diabetes and coronary artery disease). This started after training in February 2008 and continued until the end of the project in December 2009. Provision of diagnostic facilities (ECG, blood sugar and cholesterol measurement using strips) and drugs (glibenclamide, metformin, enalapril, simvastatin, chlorthiazide and low-dose aspirin) were also part of the strengthening. The Civil Hospital Ballabgarh had a weekly NCD clinic running under the supervision of a physician, and new NCD clinics were started in the PHCs.¹² A tobacco-cessation and diet-counselling clinic was started for three days a week at Ballabgarh hospital, wherein trained medical social workers provided individual as well as group counselling. The same counsellors provided counselling facilities at the PHCs on the respective days of the NCD clinics. The model adopted for health-facilities strengthening, along with individual NCD screening and lifestyle advice by health workers, is summarized in Table 1. The patients were asked to return every week for follow-up for counselling for the first one month, and monthly thereafter.

Measurement of outcomes

The study compared the usefulness of the two approaches of risk assessment, in terms of their yield (number of new NCD patients found) and the cost incurred. The costs included in calculations were workers' time (based on proportionate allocation of salaries), the cost of new equipment (tension tapes, body meters, ECG machine and glucometer) and consumables (risk-assessment forms, ECG jelly, glucometer strips, batteries). The equipment and consumables were valued at their procurement price. The annual equivalent costs of equipment were estimated using a discount rate of 5%, assuming a useful life of 3 years, for the year 2009. The cost of training was not included, as it would be the same in both approaches. Cost estimates excluded capital costs of health facilities and equipment already available (weighing machine and blood pressure apparatus).

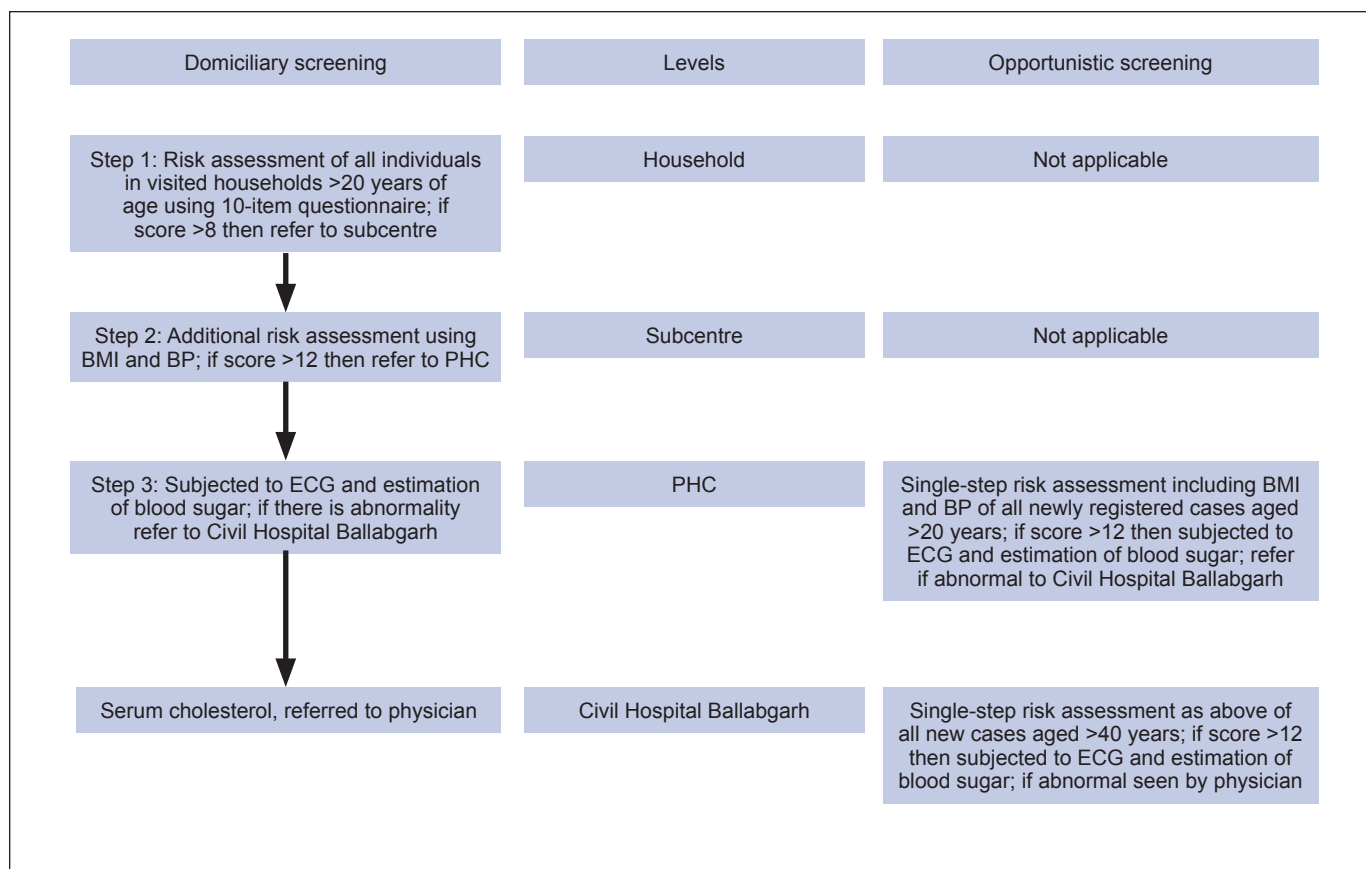


Figure 1: Diagrammatic representation of the two modes of screening

BMI: body mass index; BP: blood pressure; ECG: electrocardiography; PHC: primary health centre.

Table 1: Model for strengthening the primary health-care system for provision of NCD services

Level	Activity/services		Strengthening elements
	Diagnosis/testing	Management	
Household level	Risk assessment; suspect disease and refer	Health education and interpersonal communication, ensuring drug compliance	Training
Subcentre	BMI and blood pressure measurement	Preliminary counselling by health workers and referral of high-risk cases; follow-up during weekly clinics, drug provision	Equipments for risk assessment; digital blood pressure measuring device; drugs
Primary health centre	Blood sugar; ECG; serum cholesterol (trial)	Weekly counselling, assessment and treatment by medical officer	Glucometer, ECG machine, serum cholesterol analyser, first-line drugs
Secondary-level hospital, Ballabgarh	Serum cholesterol; review of case by physician	Management by physician; individual counselling	Necessary equipment (already available); counsellor; second-line drugs

BMI: body mass index; ECG: electrocardiography.

Assessment of workload and performance of workers

In order to estimate the time spent by workers in different health domains/work categories, time–motion analyses were carried out at baseline (November to December 2007) and at the end of the study (June 2009), after one full year of implementation. Six subcentres were randomly selected and both the male and female health workers were studied. At the end of the study, again, six subcentres were selected randomly but only seven health workers were available on the days of visit. During the assessment, workers selected for the day were accompanied from their starting point in the village until they returned to their subcentres after completing their household visits. All the activities that were carried out in each household were noted in a structured observation sheet. Additionally, each activity was timed using a stop-watch and the time spent was noted in the structured sheet. Fixed immunization days and “pulse polio” days were excluded from the study. The impact of NCD activities at macro level was assessed by looking at coverage or performance indicators of major national programmes in the field practice area for a 5-year period starting 2 years before the project, up to the end of the project. The data for these are reported annually and were sourced from annual reports of the All India Institute of Medical Science.¹³ At the end of the study in December 2009, MPHWs were asked to fill in a feedback form on their perspectives on introduction of NCD activities in their workplan.

RESULTS

Workload on multipurpose health workers (see Table 2)

At both baseline and the end of the study, the time–motion study showed that the workers were spending an average of 3–3.5 h in the field, covering about 45–50 houses, of which

an average of 32 had potential recipients of services at home. Workers then spent about 2 h in the afternoon in the subcentre in record keeping and planning the next day’s work. Almost 40% of the time was spent in travelling and general enquiries. Reproductive and child health activities together accounted for 18.2% of the time and malaria surveillance 12% of the total field time. Ill-defined work categories like health education or others (like meeting members of the village health and sanitation committee) accounted for 25% of the time and showed the maximum decline at the end of the study. About 6% of workers’ time was spent in NCD-related activities at the end of the study, which translated to about 12 min of work, or 1–2 risk assessments, in a day. There was an increase in maternal care and tuberculosis work, probably reflecting the increased emphasis on these at national level. Coverage with major immunizing agents and antenatal registration were sustained above 95% after the introduction of the NCD activities. The number of cases of tuberculosis detected annually, and the annual blood examination rate for malaria, also remained unchanged during this period.

Feedback from health workers

All 28 health workers recognized the need to address NCDs as the number of patients was increasing. They rated the training they received as appropriate and informative. However, as this area was new, they suggested retraining sessions every 2–3 months to reinforce information. Overall, they reported that the community appreciated this service and taking of “measurements”. Some of the problems reported were lack of medicines at subcentres (these were made available at PHCs), as only richer people could go to a PHC or Ballabgarh, owing to poor transport for regular treatment. Compliance with treatment was a problem reported, and the health workers stressed the need for community education. The health workers said that they were able to do only 1–2 risk assessments in a day, as otherwise other programme work was affected. They,

Table 2: Result of time–motion analysis at baseline and the end of the study

Work category	Proportion (%) of time spent in the work category	
	Baseline (Nov–Dec 2007)	End of study (June 2009)
Number of MPHWs covered (households visited)	12 (384)	7 (216)
Travelling between houses and waiting at homes	23.3	21.3
Rapport building and general enquiry	17.1	16.8
Child care	5.4	6.8
Maternal care	6.5	10.8
Contraception advice	6.3	7.2
Collection of vital statistics	3.8	2.0
Health education	9.2	5.5
Tuberculosis case-finding and treatment	0.8	4.1
Malaria surveillance	12.0	9.2
Others	15.5	10.6
Noncommunicable disease prevention and control	0.0	5.7

MPHW: multipurpose health worker.

therefore, felt that, rather than adding more workload on them, there should be a rationalization of their workload. They suggested either a reduction in the number of houses to be visited daily, or lower targets for other programmes, especially blood smears for all cases of fever.

Comparison of screening strategies (see Table 3)

Domiciliary approach

In three months, two research workers screened 6068 subjects aged over 20 years at their homes in the two villages. Of these, 1687 (27.8%) were found to have a score of more than 8 and asked to come to the subcentre. Only 633 (37.5%) of those asked came to the subcentre and of these 633 subjects, 82 (12.9%) scored more than 12 and had to be referred to a PHC. Of these 82, only 27 (32.9%) complied with the referral and among them, 8 patients were diagnosed with NCDs, giving a rate of detection of 1.3 cases of NCDs for each 1000 screened at domiciliary level.

Opportunistic screening

In the opportunistic screening occurring at PHCs, a total of 4454 subjects aged over 20 years were screened and 820 (18.4%) were found to be at “high-risk”, i.e. with a score of more than 12. Among these, 138 cases of NCDs were identified (16.8%), giving a case-detection rate of 31.0 per 1000 screened. At the Civil Hospital Ballabgarh, 5380 of the outpatient attendees above 40 years of age were screened; 24.3% were identified as “at risk” and further investigated; and 323 cases were detected, giving a case-detection rate of 60.0 per 1000.

Cost of screening (see Table 3)

The cost per screening increased as the level of screening increased, with the lowest cost being at domiciliary level (₹28.8; US\$ 0.48 @ US\$ 1 = ₹60), and the highest at subdistrict hospital level (₹47.71; US\$ 0.80). However, the cost-effectiveness ratio decreased as the level of health facility increased. In comparison to domiciliary screening, opportunistic screening at subdistrict level was 27.5 times and opportunistic screening at PHC was 15.0 times more cost-effective.

Table 3: Cost-effectiveness of the two approaches of screening at Ballabgarh

Description of screening strategy		Domiciliary, by research worker at homes (two-level); individuals aged >20 years	Opportunistic, by research worker (single level)	
			At PHCs; individuals aged >20 years	At Civil Hospital; individuals aged >40 years
Indicator	Definition of indicator			
Sample size	Individuals whose risk assessment was done	6068	4454	5380
Proportion with risk at first-stage assessment, <i>n</i> (%)	Above cut-off score of 8	1687 (27.8%)	Not applicable	Not applicable
Compliance with reporting to subcentre, <i>n</i> (%)	Proportion who attended among those called	633 (37.5%)	Not applicable	Not applicable
Proportion with risk with full assessment, <i>n</i> (%)	Total score over 12	82 (13%)	820 (18.4%)	1329 (24.7%)
Compliance with referral to PHC, <i>n</i> (%)	Proportion who attended among those referred	27 (33%)	Not applicable	Not applicable
NCD cases identified, <i>n</i> (%)	Individuals with abnormal ECG or blood sugar	8 (29.6%)	138 (16.8%)	323 (24.3%)
Case-detection rate, per 1000	Case detected per 1000 screened	1.3	31.0	60.0
Screening cost, ₹ (US\$)	Total cost incurred	174 645 (2910.7)	201 135 (3352.2)	256 656 (4277.6)
Cost per screening, ₹ (US\$)	Cost per person screened	28.78 (0.48)	45.16 (0.75)	47.71 (0.80)
Cost-effectiveness ratio, ₹ (US\$)	Cost per NCD case identified	21 830.6 (363.8)	1457.5 (24.3)	794.6 (13.2)

ECG: electrocardiography; NCD: noncommunicable disease; PHC: primary health centre.

Health-facility utilization

During the period 2008–2009, 146 newly diagnosed patients and other previously known patients with diabetes and hypertension were treated at the two PHCs. A total of 960 subjects were counselled for tobacco cessation and modifications to diet and physical activity, and the holding rate and the mean number of counselling sessions per subject was about two (see Table 4). In addition to diagnostic facilities, free drugs were distributed to all patients.

DISCUSSION

This study illustrates the feasibility of integrating NCD prevention and control into primary health care. It shows that there is scope in the health workers' schedule for introduction of work related to NCDs. The workers understood the need for taking up NCD work but resisted it as additional work. Resistance to work seen as "additional" is a known factor for difficulties in implementing changes.¹⁴ Though additional monetary incentive for this could address such resistance, it would be more appropriate to restructure and rationalize the workers' schedules to accommodate NCD-related work. However, the study also found the actual time spent on NCD work was quite low, perhaps reflecting the current priority levels. In order to better utilize workers' time, one could conceivably look at village-based community health workers to do part of the work related to risk assessment, interpersonal communication and follow-up of patients. This was attempted in the second phase of the study and results will be presented in due course.

The NPCDCS focus is largely on health-facility-based interventions at district level and it advocates opportunistic screening at health facilities and a camp approach for risk screening at population level.¹⁵ As of 31 March 2014, as per the data received from individual states, a total of 5 539 571 persons have been screened for diabetes and hypertension under

various health facilities, schools, workplaces and urban slums. An average of 6.15% were suspected to have diabetes (random blood sugar above 140 mg/dL) and an average of 5.12% were found to be either pre-hypertensive or hypertensive.¹⁶ A qualitative study conducted at a subcentre in Ambala found that there was no focus on health-promotion activities. The subjects were not sure as to why the camp was being held and some had anxiety related to a positive test result.¹⁷

This paper found that the opportunistic screening was more cost-effective than domiciliary screening. The main problem with domiciliary screening was poor compliance with referral. Roughly, only one third complied with advice for referral at both the stages (home to subcentre and subcentre to PHC). This was also the reason why there was a lower unit cost of screening at domiciliary level, as lower costs were incurred at higher levels of the health system, because only a few subjects reached this level. Similar compliance rates for diabetes screening have been reported by others in India and other countries.^{18,19} The reason for poor compliance is poor perception of risk, combined with the inconvenience of complying with referral. Increasing awareness and motivation by accredited social health activists could overcome this problem. While the results of this study provide support for the opportunistic screening being carried out under NPCDCS, the choice between opportunistic, domiciliary or camp approaches can vary by context or situation. The higher efficiency at the Civil Hospital Ballabgarh was partly due to the fact that only individuals aged over 40 years were screened and the proportion of people at risk usually increases with age. However, it should be noted that the best period for counselling for many of these behaviours is early adulthood.

The World Health Organization (WHO) has developed a package of essential noncommunicable (PEN) disease interventions for primary health care in low-resource settings.²⁰ PEN identifies core technologies, medicines and risk-prediction tools, and provides technical and operational outlines for integration of essential NCD interventions into primary care. The experience

Table 4: Services utilization under the project, by health-facility levels (2008–2009)

Services	PHCs	Civil Hospital Ballabgarh
Estimated adult attendance at outpatient department in one year	15 000	54 686
Opportunistic screening, <i>n</i> (% of outpatient attendance)	4454 (29.7%)	5380 (9.8%)
Blood sugar <i>n</i>	998	Tests routinely done and therefore not reported separately as done
Electrocardiography, <i>n</i>	518	
New cases put on treatment, <i>n</i>	146	323
People started on counselling, <i>n</i>	960	1280
Counselling sessions held, <i>n</i>	1629	2347
Mean number of counselling sessions per subject	1.70	1.83

PHC: primary health centre.

of its pilot testing in Bhutan shows that integration of NCDs into primary health care is feasible, though the study also reported a significant loss to follow-up of patients with NCDs, with up to 50% not coming for follow-up after three visits.²¹ While not exactly following the PEN guidelines (as they were introduced after this study), this study has used similar components.

Another key research issue on integrating NCDs into a primary health-care system, identified by Harries et al.,²² was validating standard diagnostic protocols for NCD case-finding and assessing staff performance in the use of protocols. While the risk-assessment tool used in the present study could be different from that used by others, most of the risk-assessment tools would require similar knowledge and skills as the one used in this study. This study covered many critical operational issues for integration of NCD prevention and control into the primary health-care set-up in India. However, it did not focus on the effectiveness of this intervention in control of NCDs, as the blood pressure and blood sugar levels of patients were not monitored. The small number of health workers and facilities is also a limitation.

This study has shown that, with sufficient strengthening by provision of basic technologies and medicines, PHCs can be a nodal agency for provision of NCD services. The availability of essential medicines and basic technologies at primary care facilities is one of the nine indicators with targets under the national and global NCD monitoring frameworks.^{23,24} Currently, the NPCDCS has no identified role for PHCs. This needs to be corrected. The role of counselling is critical for changing the behaviours of those at risk. However, counselling services are not available. This study used weekly visits by a counsellor based in the district hospital, to provide part-time counselling for NCDs. Another approach would be to use the integrated counselling and treatment centres (ICTCs) for HIV counselling, to also provide NCD counselling.

CONCLUSION

It is possible to integrate NCD prevention and control into primary health care in India. Opportunistic screening appears to be feasible and a cost-effective strategy for risk screening. A strengthened PHC can serve as a focal point for NCD prevention and control.

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Regional variation in maternal and childhood undernutrition in Bangladesh: evidence from demographic and health surveys

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ABSTRACT

Background: Undernutrition among mothers and children is currently a major public health and development concern in Bangladesh. In literature relating to nutritional determinants, of particular interest is the geography, as regions with poor nutrition tend to pull down the overall nutritional status of the country. As such, reducing the regional gap can alone reduce overall undernutrition significantly, especially when regional gaps are high. The aim of this study is, therefore, to assess the magnitude of inequalities in undernutrition in children aged under 5 years in Bangladesh and their mothers, and relate this to the administrative divisions of the country.

Methods: The Bangladesh Demographic and Health Surveys (1996–1997, 1999–2000, 2004 and 2007) were the sources of data, and a total of 16 278 mother–child pairs whose records were complete for the required individual and household-level variables were included in the analysis. Maternal nutritional status was measured by the body mass index (BMI). Weight-for-age, height-for-age and weight-for-height z-scores were calculated by use of the World Health Organization (WHO) Child Growth Standards to assess the nutritional status of children aged under 5 years. General linear model, sequential linear and multinomial logistic regression analyses were done to assess the inequalities in maternal and child nutritional status among the six administrative divisions of Bangladesh. Socioeconomic variables that were controlled for were residency, education and occupation of the mothers and their husbands, house type and possession score in the household.

Results: Maternal BMI and prevalence of underweight, stunting and wasting in children aged under 5 years were found to vary significantly according to administrative division. Of the six divisions, Sylhet was found to have highest prevalence of undernourished mothers and children. The trends from 1996 to 2007 also established Sylhet as the poorest-performing region overall.

Conclusion: The Sylhet administrative division needs specially focused attention from policy-makers if the overall performance of the health, nutrition and population sector is to reach the targets set by the country.

Key words: administrative divisions, Bangladesh, undernutrition, WHO Child Growth Standards

BACKGROUND

Undernutrition among mothers and children is currently a major public health and development concern in Bangladesh.¹ In 2012 the World Food Programme reported that about

2 million, or some 14% of children aged under 5 years in Bangladesh, had acute undernutrition (wasting), close to the World Health Organization's (WHO) "critical" threshold of 15%.² Reproductive health, child health and nutrition are core priorities for any country,³ and more so for Bangladesh, as it

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has one of the world's greatest burdens of maternal, newborn and child undernutrition. Understanding the nature and determinants of undernutrition is essential in contemplating the health of populations in the country and in allocating resources appropriately to improve the health of the poor and most vulnerable groups. In literature relating to nutritional determinants, of particular interest is the geography, as regions with poor nutrition tend to pull down the overall nutritional status of the country. As such, reducing the regional gap can alone reduce overall undernutrition significantly, especially when regional gaps are high. According to Simler,⁴ estimates of nutritional status from national surveys for large areas have typically masked the high within-country variability, including pockets of severe undernutrition or "hunger hot spots"; whereas developing policies and programmes to improve nutritional status requires a more disaggregated picture of undernutrition, especially when policies recommend moving to greater levels of decentralization. Earlier evidence has offered strong support for geographic targeting of social programmes and it has documented substantial improvements in programme impact through geographic targeting of needs-based programmes.^{5,6}

The administration of Bangladesh is currently divided into eight major divisions, whereas, during the period (1996–2007) from which the data for these analyses were drawn, there were six administrative divisions: Dhaka, Chittagong, Rajshahi, Barisal, Khulna and Sylhet. As each division has different characteristics in terms of geography, economy and social structure, it tends to offer different opportunity structures for people living there. Opportunity structure, in social science, refers to the societal structure that provides opportunities such as quality education, transportation, community well-being, and income generation for its people to live a successful life.⁷ Biswakarma⁸ anticipated interregional inequality in undernutrition as one of the outcomes of such differential opportunity structures.

Recent mapping of undernutrition in Bangladesh has reported regional concentration of undernutrition, leading to the suggestion of geographic targeting of nutrition interventions, which, in the opinion of the authors, could result in a high pay-off in achieving significant reductions in the number and rate of undernourished children.⁹

The aim of this study is, therefore, to assess the inequalities in nutritional status of mother–child pairs in the six administrative divisions of Bangladesh.

METHODS

Sampling

The Bangladesh Demographic and Health Surveys (BDHS) conducted in 1996–1997, 1999–2000, 2004 and 2007 were the source of data,^{10–13} and they contained information on 9127, 10 544, 11 440 and 10 996 households, respectively. The present study focused on the nutritional status of children aged under 5 years and their mothers. Therefore, only those families with children aged under 5 years were considered for the study, and 5507, 6217, 6612 and 6031 households were selected from the 1996–1997, 1999–2000, 2004 and 2007 surveys, respectively. Children and mothers for whom there were no data on height, weight, age or sex were excluded from the study. Anthropometric measurements of above or below 4 standard deviations (SD) from the mean for the mothers were considered to be outliers and were excluded from the analysis.¹⁴ Nutritional status of the children was measured using *z*-scores, and the cut-off values recommended in the 2006 WHO Child Growth Standards for data exclusion were used; thus, data were excluded if the *z*-score for a child's height-for-age (HAZ) was below –6 or above +6, weight-for-age (WAZ) was below –6 or above +5, or weight-for-height (WHZ) was below –5 or above +5, because these extreme values were most likely to be the result of errors in measurement or data entry.¹⁵ Lastly, children and women for whom information was lacking on the selected socioeconomic and demographic variables of the study were excluded.

Data

Ultimately, a total of 16 278 mother–child pairs, whose records were complete in the required individual and household-level variables, were included in the analysis, of whom 3560 were from the 1996–1997 survey (later referred to as 1996), 4039 were from 1999–2000 (later referred to as 2000), 4731 were from 2004, and 3948 were from the 2007 BDHS (see Table 1).

Table 1: Step-wise process of selecting mother–child pairs with complete information

Steps of selection	Bangladesh Demographic and Health Survey by year			
	1996	2000	2004	2007
Total households	9127	10 544	11 440	10 996
Had a child aged under 5 years in the family	5507	6217	6612	6031
Had child height, weight and age information	3974	4392	4874	4491
Calculation of <i>z</i> -scores of height-for-age, weight-for-age and weight-for-height	3898	4321	4852	4483
Excluded because <i>z</i> -scores were outside WHO cut-off values	3700	4226	4790	4422
Had maternal height and weight information	3687	4214	4773	4412
Were excluded because maternal height and weight outside ± 4 SD	3640	4177	4765	4385
Had socioeconomic and demographic variables	8944	10 211	11 356	10 035
Had all variables	3560	4039	4731	3948
Compliant group total	16 278			

SD: standard deviation.

A cut-off value of -2.00 SD for WAZ, WHZ and HAZ was used to classify a child as underweight, wasted or stunted, respectively.

Maternal nutritional status variables compared overall mean and SD of height, weight and body mass index (BMI). Mothers' BMI values were graded into four groups: underweight (<18.50), normal ($18.50-24.99$), overweight ($25.00-29.99$) and obese (≥ 30.00), using the international WHO cut-off values.¹⁶ Four further categories of BMI were also used, according to recommendations of a WHO expert consultation on cut-off values in Asian populations, where the underweight level was similar to the WHO cut-off value, but the ranges for normal, overweight and obese were lowered to $18.50-22.99$, $23.00-27.49$ and ≥ 27.50 , respectively.¹⁷

Statistical analysis

To assess regional inequalities, six administrative "divisions" were used as the independent variable, namely Dhaka, Chittagong, Barisal, Khulna, Rajshahi and Sylhet.

All continuous data were checked for skewness using the Cox test (coefficient of skewness divided by standard error of skewness) as well as examination of the mean–median difference and the frequency distribution with a normal curve. The general linear model or the multiple regression model was used to analyse continuous outcomes with predictor variables. When the z -scores and maternal BMI values were analysed as categorical variables, logistic regression analyses, binary or multinomial, were undertaken with the explanatory variables.

Analyses were performed with two levels of adjustment: (i) analysis 1: adjusting for the period of the demographic survey and age (considered as both linear and quadratic functions), and accounting for the interaction between the period of the survey and age (considered as both linear and quadratic functions); (ii) analysis 2: in addition to all factors considered in analysis 1, all other explanatory variables in the model were adjusted for – residence (urban/rural); education and occupation of parents; housing condition (type of floor, wall and roof); ownership of assets such as radio, television, bicycle, motorcycle or telephone; availability of electricity, water supply, latrine; and number of family members; further, the effect of administrative division was tested.

IBM SPSS 20 software was used for all data analysis. The level of significance was taken to be $P \leq 0.05$.

RESULTS

Table 2 presents the mean z -scores for children, and prevalence of underweight, stunting and wasting for the six administrative divisions and for the four BDHS of 1996, 2000, 2004 and 2007. It shows that the mean WAZ of children residing in either Chittagong or Dhaka improved between 1996 and 2007, whereas the mean HAZ in all six administrative divisions showed an overall improvement over the study period. The mean WHZ of children in Sylhet, Rajshahi, Barisal and Khulna fell between 1996 and 2007. Overall mean WAZ and

HAZ values were better in children from Khulna, and lowest in children from Sylhet. Table 2 also shows that there were substantial decreases in the percentages of undernourished children over the period of the four surveys: in 1996–1997, half of the children were underweight and almost three fifths of children were stunted, whereas in 2007 almost 60% of children fell into normal categories for both WAZ and HAZ. The rate of stunting showed a decreasing trend in all six administrative divisions throughout the study period, whereas although the number of underweight children declined in all divisions between 1996 and 2000, it did not show an improvement afterwards in any of the divisions except Sylhet. Unexpectedly, the percentage of children with wasting showed an increasing trend in all administrative divisions after 2000. In Sylhet and Barisal, there were higher prevalence rates of underweight and stunting compared with other divisions. The declines in rates of underweight, stunting and wasting were highest in Sylhet, at 13.6%, 19.0% and 7.1%, respectively.

In the pooled data of all four BDHS, the mean prevalence of children aged under 5 years with underweight, stunting or wasting was found to vary significantly according to administrative division. The overall prevalence of stunting ranged from 50.3% in Barisal to 40.4% in Khulna. Sylhet had the highest prevalence of wasting (19.9%) and Barisal had the lowest prevalence (14.7%). The overall prevalence of underweight children ranged from 45.8% in Sylhet to 35.1% in Khulna (data not shown).

Regional heterogeneity was also observed in pooled data: the mean HAZ score was found to be significantly higher in Khulna ($P < 0.001$) and Rajshahi ($P < 0.05$) divisions compared with that in Sylhet (see Table 3). For both WAZ and WHZ, children from Sylhet had the lowest mean values (-1.59 and -0.92 , respectively), whereas those from Khulna and Dhaka had the highest mean values for WAZ and WHZ, respectively (see Table 3). Binary logistic regression analysis in Table 4 shows that children from Dhaka, Rajshahi and Khulna had significantly lower odds of being underweight (odds ratio [OR] 0.86, 0.84 and 0.74, with P values of <0.05 , <0.01 and <0.001 , respectively) compared with Sylhet. Children from Dhaka (OR 0.74, $P < 0.001$) and Rajshahi (OR 0.85, $P < 0.05$) showed less likelihood of being wasted, and those from Khulna (OR 0.76, $P < 0.001$) and Rajshahi (OR 0.79, $P < 0.001$) showed less likelihood of being stunted compared with children from Sylhet.

Regional variation among the administrative divisions was also found to be present in maternal nutritional status; the mean values for maternal height (centimetres), weight (kilograms) and BMI (kilograms per square metre); and the prevalence of underweight, overweight and obese mothers by administrative division for the four survey periods are presented in Table 5.

Mean height, weight and BMI were lowest in Sylhet. Mothers from Khulna and Chittagong were, on average, over 1 kg heavier compared with mothers from Sylhet (see Table 5). The multinomial logistic regression analysis in Table 7 shows that mothers from all the other five divisions had significantly lower odds of being underweight compared with mothers from Sylhet, but not lower odds for being overweight.

Table 2. Mean z-scores and prevalence of underweight, stunting and wasting for children in administrative divisions, from the Bangladesh Demographic and Health Surveys of 1996, 1999, 2004 and 2007

Year	Division (n)	WAZ Mean z-score (SD)	HAZ Mean z-score (SD)	WHZ Mean z-score (SD)	Underweight (≤ -2.00 SD WAZ) n (%)	Stunting (≤ -2.00 SD HAZ) n (%)	Wasting (≤ -2.00 SD WHZ) n (%)	Proportion underweight, stunted, or wasted n (%)
1996	Barisal (369)	-1.97 (1.28)	-2.32 (1.54)	-0.89 (1.44)	193 (52.3)	227 (61.5)	76 (20.6)	268 (72.6)
	Chittagong (599)	-2.05 (1.36)	-2.13 (1.66)	-1.16 (1.42)	308 (51.4)	315 (52.6)	162 (27.0)	413 (68.9)
	Dhaka (1003)	-1.95 (1.26)	-2.22 (1.61)	-0.97 (1.31)	488 (48.7)	582 (58.0)	194 (19.3)	675 (67.3)
	Khulna (382)	-1.82 (1.16)	-1.98 (1.39)	-0.99 (1.36)	171 (44.8)	189 (49.5)	85 (22.3)	250 (65.4)
	Rajshahi (835)	-1.97 (1.18)	-2.13 (1.51)	-1.05 (1.29)	414 (49.6)	477 (57.1)	176 (21.1)	588 (70.4)
	Sylhet (372)	-2.14 (1.40)	-2.40 (1.67)	-1.10 (1.59)	207 (55.6)	228 (61.3)	105 (28.2)	285 (76.6)
	Total (3560)	-1.98 (1.27)	-2.19 (1.58)	-1.03 (1.38)	1781 (50.0)	2018 (56.7)	798 (22.4)	2479 (69.6)
2000	Barisal (347)	-1.64 (1.20)	-1.75 (1.47)	-0.91 (1.09)	133 (38.3)	153 (44.1)	45 (13.0)	181 (52.2)
	Chittagong (839)	-1.65 (1.17)	-1.80 (1.46)	-0.87 (1.08)	323 (38.5)	386 (46.0)	107 (12.8)	465 (55.4)
	Dhaka (1002)	-1.68 (1.15)	-1.90 (1.46)	-0.81 (1.08)	385 (38.4)	481 (48.0)	122 (12.2)	569 (56.8)
	Khulna (621)	-1.51 (1.08)	-1.71 (1.24)	-0.76 (1.07)	198 (31.9)	260 (41.9)	73 (11.8)	312 (50.2)
	Rajshahi (752)	-1.75 (1.13)	-1.86 (1.41)	-0.96 (1.08)	302 (40.2)	343 (45.6)	114 (15.2)	430 (57.2)
	Sylhet (478)	-1.89 (1.20)	-1.99 (1.50)	-1.03 (1.06)	215 (45.0)	242 (50.6)	76 (15.9)	285 (59.6)
	Total (4039)	-1.68 (1.15)	-1.84 (1.43)	-0.88 (1.08)	1556 (38.5)	1865 (46.2)	537 (13.3)	2242 (55.5)
2004	Barisal (547)	-1.69 (1.14)	-2.04 (1.34)	-0.71 (1.05)	215 (39.3)	280 (51.2)	51 (9.3)	310 (56.7)
	Chittagong (978)	-1.75 (1.20)	-1.87 (1.44)	-0.95 (1.16)	415 (42.4)	460 (47.0)	164 (16.8)	563 (57.6)
	Dhaka (1027)	-1.66 (1.15)	-1.85 (1.38)	-0.86 (1.14)	398 (38.8)	483 (47.0)	132 (12.9)	580 (56.5)
	Khulna (662)	-1.55 (1.09)	-1.57 (1.29)	-0.92 (1.15)	222 (33.5)	256 (38.7)	106 (16.0)	341 (51.5)
	Rajshahi (964)	-1.73 (1.14)	-1.77 (1.32)	-1.03 (1.13)	379 (39.3)	423 (43.9)	161 (16.7)	528 (54.8)
	Sylhet (553)	-1.78 (1.15)	-1.88 (1.49)	-0.97 (1.15)	243 (43.9)	270 (48.8)	92 (16.6)	336 (60.8)
	Total (4731)	-1.70 (1.15)	-1.82 (1.38)	-0.92 (1.14)	1872 (39.6)	2172 (45.9)	706 (14.9)	2658 (56.2)
2007	Barisal (537)	-1.79 (1.10)	-1.80 (1.35)	-1.07 (1.09)	233 (43.4)	246 (45.8)	93 (17.3)	317 (59.0)
	Chittagong (768)	-1.74 (1.21)	-1.76 (1.46)	-1.03 (1.12)	317 (41.3)	338 (44.0)	141 (18.4)	420 (54.7)
	Dhaka (847)	-1.59 (1.20)	-1.68 (1.40)	-0.89 (1.13)	325 (38.4)	356 (42.0)	125 (14.8)	452 (53.4)
	Khulna (517)	-1.53 (1.11)	-1.40 (1.39)	-1.04 (1.12)	174 (33.7)	177 (34.2)	92 (17.8)	249 (48.2)
	Rajshahi (676)	-1.72 (1.03)	-1.66 (1.16)	-1.11 (1.05)	280 (41.4)	268 (39.6)	119 (17.6)	370 (54.7)
	Sylhet (603)	-1.81 (1.15)	-1.75 (1.48)	-1.15 (1.16)	253 (42.0)	255 (42.3)	127 (21.1)	350 (58.0)
	Total (3948)	-1.69 (1.14)	-1.68 (1.38)	-1.04 (1.12)	1582 (40.1)	1640 (41.5)	697 (17.7)	2158 (54.7)

SD: standard deviation; HAZ: height-for-age; WAZ: weight-for-age; WHZ: weight-for-height.

Table 3: Relationship between z-scores and the demographic and socioeconomic variables for the pooled data

z-score	Administrative division	Analysis 1 ^a			Analysis 2 ^b		
		Mean	SE	Significance ^c	Mean	SE	Significance ^c
WAZ	Barisal	-1.76	0.03	<0.005	-1.52	0.04	NS
	Chittagong	-1.79	0.02	<0.01	-1.57	0.04	NS
	Dhaka	-1.72	0.02	<0.001	-1.47	0.04	<0.005
	Khulna	-1.57	0.03	<0.001	-1.39	0.04	<0.001
	Rajshahi	-1.79	0.02	<0.005	-1.46	0.04	<0.005
	Sylhet (reference)	-1.91	0.03		-1.59	0.04	
HAZ	Barisal	-1.95	0.03	NS	-1.68	0.05	NS
	Chittagong	-1.91	0.02	NS	-1.67	0.05	NS
	Dhaka	-1.91	0.02	NS	-1.65	0.04	NS
	Khulna	-1.62	0.03	<0.001	-1.45	0.05	<0.001
	Rajshahi	-1.84	0.02	<0.001	-1.51	0.05	<0.05
	Sylhet (reference)	-2.01	0.03		-1.64	0.05	
WHZ	Barisal	-0.90	0.03	<0.001	-0.77	0.05	<0.01
	Chittagong	-0.99	0.02	NS	-0.87	0.04	NS
	Dhaka	-0.88	0.02	<0.001	-0.75	0.04	<0.001
	Khulna	-0.92	0.03	<0.005	-0.80	0.04	<0.05
	Rajshahi	-1.04	0.02	NS	-0.85	0.04	NS
	Sylhet (reference)	-1.06	0.03		-0.92	0.04	

NS: not significant; SE: standard error.

^a Adjustment made for the period of the demographic survey, linear and quadratic effects of age and interaction between the period of the survey, and linear and quadratic effects of age.

^b The socioeconomic and demographic information controlled for in analysis 2 were residence (urban/rural); education and occupation of parents; housing condition (type of floor, wall and roof); ownership of assets such as radio, television, bicycle, motorcycle or telephone; availability of electricity, water supply, and latrine; and number of family members; linear and quadratic terms of age and period of survey and their interactions were also entered into the analysis before testing the effect of administrative division.

^c The mean difference is significant at the 0.05 level and a Bonferroni adjustment was made for multiple comparisons.

Table 4: Binary logistic regression analysis of z-scores by demographic and socioeconomic variables

Variable	Administrative division	Analysis 1 ^a			Analysis 2 ^b		
		OR	95% CI	P value	OR	95% CI	P value
Underweight (≤ -2.00 SD WAZ)	Barisal	0.85	0.74–0.96	<0.001	0.94	0.82–1.08	<0.001
	Chittagong	0.88	0.78–0.98		1.01	0.90–1.14	
	Dhaka	0.77	0.69–0.86		0.86	0.76–0.97	
	Khulna	0.61	0.53–0.69		0.74	0.65–0.85	
	Rajshahi	0.81	0.73–0.91		0.84	0.74–0.95	
	Sylhet (reference)						
Stunting (≤ -2.00 SD HAZ)	Barisal	0.94	0.83–1.08	<0.001	1.04	0.90–1.20	<0.001
	Chittagong	0.87	0.77–0.97		1.01	0.89–1.14	
	Dhaka	0.85	0.76–0.96		0.95	0.84–1.08	
	Khulna	0.60	0.53–0.68		0.76	0.66–0.87	
	Rajshahi	0.77	0.68–0.86		0.79	0.70–0.90	
	Sylhet (reference)						
Wasting (≤ -2.00 SD WHZ)	Barisal	0.71	0.59–0.84	<0.001	0.76	0.63–0.90	<0.001
	Chittagong	0.90	0.78–1.04		0.96	0.83–1.11	
	Dhaka	0.70	0.61–0.81		0.74	0.64–0.86	
	Khulna	0.84	0.72–0.99		0.92	0.78–1.09	
	Rajshahi	0.87	0.75–1.01		0.85	0.73–0.99	
	Sylhet (reference)						

CI: confidence interval; HAZ: height-for-age; OR: odds ratio; SD: standard deviation; WAZ: weight-for-age; WHZ: weight-for-height.

^a Adjustment made for periods of demographic survey, linear and quadratic effects of age and interaction between period of survey, and linear and quadratic effects of age.

^b Socioeconomic and demographic information controlled for in analysis 2 were residence (urban/rural); education and occupation of parents; housing condition (type of floor, wall and roof); ownership of assets such as radio, television, bicycle, motorcycle or telephone; availability of electricity, water supply, latrine; and number of family members; linear and quadratic terms of age and period of survey and their interactions were also entered in the analysis before testing the effect of administrative division.

Table 5: Mean maternal height, weight and BMI, and prevalence of underweight, overweight and obesity, among mothers by administrative division, from the Bangladesh Demographic and Health Surveys of 1996, 1999, 2004 and 2007

Year	Administrative division (n)	Maternal height (cm) Mean (SD)	Maternal weight (kg) Mean (SD)	Maternal BMI (kg/m ²) Mean (SD)	Underweight n (%)	Overweight n (%)	Obese n (%)
1996	Barisal (369)	150.05 (5.53)	42.81 (6.57)	18.99 (2.55)	183 (49.6)	23 (6.2) (6.2)	2 (0.5)
	Chittagong (599)	150.65 (5.33)	43.49 (7.36)	19.13 (2.90)	285 (47.6)	44 (7.3)	11 (1.8)
	Dhaka (1003)	150.23 (5.66)	42.89 (6.88)	18.98 (2.67)	495 (49.4)	68 (6.8)	11 (1.1)
	Khulna (382)	150.73 (5.51)	43.23 (6.73)	18.99 (2.50)	184 (48.2)	25 (6.5)	3 (0.8)
	Rajshahi (835)	150.14 (5.72)	42.32 (6.18)	18.75 (2.34)	414 (49.6)	28 (3.4)	7 (0.8)
	Sylhet (372)	149.61 (5.35)	41.76 (6.79)	18.63 (2.62)	208 (55.9)	14 (3.8)	4 (1.1)
	Total (3560)	150.25 (5.56)	42.77 (6.77)	18.92 (2.61)	1769 (49.7)	202 (5.7)	38 (1.1)
2000	Barisal (347)	150.21 (5.18)	43.40 (6.66)	19.21 (2.62)	159 (45.8)	27 (7.8)	5 (1.4)
	Chittagong (839)	150.67 (5.43)	44.99 (7.63)	19.78 (2.93)	312 (37.2)	102 (12.2)	18 (2.1)
	Dhaka (1002)	150.27 (5.35)	44.31 (7.66)	19.59 (2.99)	419 (41.8)	99 (9.9)	23 (2.3)
	Khulna (621)	151.01 (5.37)	45.38 (7.44)	19.87 (2.83)	216 (34.8)	69 (11.1)	13 (2.1)
	Rajshahi (752)	150.19 (5.52)	43.16 (6.51)	19.11 (2.48)	340 (45.2)	43 (5.7)	9 (1.2)
	Sylhet (478)	150.15 (5.24)	42.71 (6.96)	18.91 (2.67)	243 (50.8)	26 (5.4)	7 (1.5)
	Total (4039)	150.43 (5.38)	44.14 (7.31)	19.47 (2.81)	1689 (41.8)	366 (9.1)	75 (1.9)
2004	Barisal (547)	150.41 (5.00)	44.69 (7.44)	19.71 (2.83)	204 (37.3)	53 (9.7)	9 (1.6)
	Chittagong (978)	150.57 (5.33)	45.46 (7.68)	20.02 (3.01)	332 (33.9)	111 (11.3)	28 (2.9)
	Dhaka (1027)	150.28 (5.57)	45.32 (7.96)	20.03 (3.09)	371 (36.1)	126 (12.3)	29 (2.8)
	Khulna (662)	151.09 (5.31)	46.05 (7.63)	20.16 (3.09)	205 (31.0)	97 (14.7)	16 (2.4)
	Rajshahi (964)	150.48 (5.63)	44.74 (7.35)	19.71 (2.72)	338 (35.1)	87 (9.0)	19 (2.0)
	Sylhet (553)	150.19 (5.17)	44.07 (8.18)	19.50 (3.22)	237 (42.9)	63 (11.4)	15 (2.7)
	Total (4731)	150.50 (5.39)	45.11 (7.72)	19.88 (2.99)	1687 (35.7)	537 (11.4)	116 (2.5)
2007	Barisal (537)	150.79 (5.58)	45.31 (7.16)	19.90 (2.82)	180 (33.5)	48 (8.9)	13 (2.4)
	Chittagong (768)	150.68 (5.35)	46.95 (8.55)	20.64 (3.29)	208 (27.1)	118 (15.4)	38 (4.9)
	Dhaka (847)	150.17 (5.40)	46.26 (8.14)	20.49 (3.26)	259 (30.6)	136 (16.1)	34 (4.0)
	Khulna (517)	151.62 (5.17)	47.77 (8.25)	20.73 (3.05)	133 (25.7)	83 (16.1)	20 (3.9)
	Rajshahi (676)	150.28 (5.33)	46.02 (8.38)	20.34 (3.31)	226 (33.4)	93 (13.8)	26 (3.8)
	Sylhet (603)	150.38 (5.36)	44.72 (7.31)	19.75 (2.95)	232 (38.5)	76 (12.6)	13 (2.2)
	Total (3948)	150.59 (5.38)	46.18 (8.08)	20.33 (3.16)	1238 (31.4)	554 (14.0)	144 (3.6)

BMI: body mass index; SD: standard deviation.

Table 6: Relationship between maternal height, weight and BMI and the demographic and socioeconomic variables for the pooled data

Indicator	Administrative division	Analysis 1 ^a			Analysis 2 ^b		
		Mean	SE	Significance ^c	Mean	SE	Significance ^c
Height	Barisal	150.40	0.13	NS	150.70	0.21	NS
	Chittagong	150.62	0.10	<0.05	150.89	0.19	NS
	Dhaka	150.24	0.09	NS	150.66	0.18	NS
	Khulna	151.14	0.12	<0.001	151.22	0.20	<0.005
	Rajshahi	150.32	0.10	NS	150.70	0.18	NS
	Sylhet (reference)	150.11	0.12		150.56	0.20	
Weight	Barisal	44.15	0.18	0.013	46.55	0.26	0.652
	Chittagong	45.23	0.13	0.000	47.20	0.23	0.000
	Dhaka	44.60	0.12	0.000	46.64	0.22	0.065
	Khulna	45.82	0.16	0.000	47.16	0.24	0.000
	Rajshahi	44.15	0.13	0.002	46.89	0.23	0.001
	Sylhet (reference)	43.35	0.17		46.09	0.24	
BMI	Barisal	19.50	0.07	0.051	20.47	0.10	0.873
	Chittagong	19.92	0.05	0.000	20.71	0.09	0.000
	Dhaka	19.73	0.05	0.000	20.52	0.09	0.058
	Khulna	20.03	0.06	0.000	20.60	0.10	0.007
	Rajshahi	19.52	0.05	0.006	20.62	0.09	0.001
	Sylhet (reference)	19.22	0.07		20.30	0.10	

BMI: body mass index; NS: not significant; SE: standard error.

^a Adjustment made for the period of the demographic survey, linear and quadratic effects of age and interaction between the period of the survey, and linear and quadratic effects of age.

^b Socioeconomic and demographic factors controlled for in analysis 2 were residence (urban/rural); education and occupation of parents; housing condition (type of floor, wall and roof); ownership of assets such as radio, television, bicycle, motorcycle or telephone; availability of electricity, water supply; and latrine and number of family members; linear and quadratic terms of age and period of survey and their interactions were also entered into the analysis before testing the effect of region.

^c The mean difference is significant at the 0.05 level and a Bonferroni adjustment was made for multiple comparisons.

Table 7: Multinomial logistic regression analysis of maternal BMI by demographic and socioeconomic variables

BMI	Analysis ^a	Division	Underweight		Overweight		Obese		P value
			OR	95% CI	OR	95% CI	OR	95% CI	
WHO cut-off value	1	Barisal	0.79	0.69–0.90	0.89	0.65–1.22	0.66	0.26–1.72	<0.001
		Chittagong	0.65	0.58–0.73	1.27	0.98–1.64	1.83	0.92–3.64	
		Dhaka	0.75	0.67–0.84	1.31	1.02–1.70	1.70	0.86–3.39	
		Khulna	0.60	0.52–0.68	1.33	1.01–1.77	1.26	0.57–2.76	
		Rajshahi	0.75	0.67–0.85	1.07	0.81–1.42	1.23	0.58–2.60	
	Sylhet (reference)								
	2	Barisal	0.85	0.73–0.97	0.97	0.69–1.37	0.86	0.31–2.38	
		Chittagong	0.72	0.63–0.81	1.12	0.84–1.48	1.55	0.74–3.22	
		Dhaka	0.81	0.72–0.91	1.03	0.77–1.37	0.99	0.46–2.10	
		Khulna	0.67	0.58–0.77	0.97	0.71–1.32	0.84	0.36–1.96	
Rajshahi		0.72	0.64–0.82	1.08	0.79–1.46	1.18	0.52–2.64		
Sylhet (reference)									
Asian cut-off value	1	Barisal	0.77	0.67–0.89	0.86	0.68–1.09	0.77	0.47–1.26	<0.001
		Chittagong	0.67	0.59–0.76	1.25	1.03–1.53	1.53	1.04–2.25	
		Dhaka	0.77	0.68–0.86	1.31	1.07–1.59	1.44	0.98–2.12	
		Khulna	0.62	0.54–0.70	1.37	1.11–1.69	1.30	0.85–1.99	
		Rajshahi	0.74	0.66–0.84	0.91	0.74–1.13	1.11	0.74–1.68	
	Sylhet (reference)								
	2	Barisal	0.83	0.72–0.96	0.90	0.69–1.16	0.79	0.46–1.36	
		Chittagong	0.72	0.64–0.82	1.12	0.91–1.39	1.26	0.83–1.91	
		Dhaka	0.82	0.72–0.93	1.11	0.89–1.38	0.96	0.62–1.47	
		Khulna	0.67	0.58–0.77	1.03	0.82–1.30	0.84	0.52–1.34	
Rajshahi		0.71	0.63–0.81	0.93	0.73–1.17	1.01	0.64–1.59		
Sylhet (reference)									

BMI: body mass index; CI: confidence interval; OR: odds ratio.

^a Analysis 1: adjustment was made for the period of the demographic survey, linear and quadratic effects of age and interaction between the period of survey, and linear and quadratic effects of age; analysis 2: socioeconomic and demographic factors controlled for in analysis 2 were residence (urban/rural); education and occupation of parents; housing condition (type of floor, wall and roof); ownership of assets such as radio, television, bicycle, motorcycle or telephone; availability of electricity, water supply, and latrine; and number of family members; linear and quadratic terms of age and the period of the survey and their interactions were also entered into the analysis before testing the effect of region.

Over the four survey periods, there were linear increases in maternal mean height, weight and BMI. Height, although showing a significant overall increase (0.34 cm, $P < 0.05$) within each administrative division over the study period, remained at a constant level (data not shown), whereas BMI significantly increased within each administrative division across the period of the four surveys (see Table 5). The rates of the increase in weight and BMI were somewhat less among mothers from Sylhet (3 kg and 1.14 kg/m²), whereas the rate was highest among mothers from Khulna (4.5 kg and 1.77 kg/m²). In 2007, the prevalence of underweight mothers ranged from 38.5% in Sylhet to 25.7% in Khulna. Over the four BDHS survey periods, the decrease in the number of underweight mothers was least in Barisal (16.1%, $P < 0.001$), whereas it decreased 22.5% ($P < 0.001$) in Khulna and 20.5% in Chittagong ($P < 0.001$) (see Table 5).

DISCUSSION

Previous research in Bangladesh has reported that women living in the Sylhet region are more likely to be underweight compared with the reference region of Barisal, and women from Chittagong, Rajshahi, and Khulna are less likely to be underweight compared with those in Sylhet.¹⁸ In the present study, regional heterogeneity in maternal mean BMI and weight was observed, with the lowest mean in both these indicators in Sylhet, after controlling for all socioeconomic and demographic variables.

A recent study found that children from the Sylhet division were more likely to be severely stunted in their growth compared with children from Rajshahi, Khulna and Dhaka administrative divisions.¹⁹ Similarly, Rahman and Chowdhury²⁰ analysed the

data from BDHS 2004 and showed that children in the Sylhet division were more likely, and in the Khulna division less likely, to be chronically undernourished than children in other divisions. However, Das et al.²¹ observed the highest level of stunting in the Barisal administrative division, where about one fifth of children were severely stunted and 30% moderately stunted, while a better picture was observed in the Khulna division, where only 8.2% and 23.1% were severely and moderately stunted, respectively. The World Bank²² reported that Sylhet had the highest prevalence of underweight children in 1996–1997 (64%) and showed the slowest relative decline (11%) in numbers of underweight children between 1996–1997 and 1999–2000. Helen Keller International (HKI)²³ also reported on the large regional differences in undernutrition in Bangladesh and that over 12 years, the numbers of underweight children had reduced by 20.3% in Sylhet, but by only 14.6% in Rajshahi. Additionally, HKI²⁴ stated that the administrative divisions most in need of attention were Barisal, Sylhet and Rajshahi.²⁴ Results from the Child and Mother Nutrition Survey of Bangladesh in 2012 and the undernutrition mapping exercise by the World Food Programme⁹ showed that both stunting and underweight rates at administrative division level were highest in Sylhet, followed by Chittagong. The present study concurred with this, and also the HKI²³ finding, with Sylhet mostly, and Barisal as well, needing the most attention from the policy-makers to decrease interregional disparity.

There were, however, paradoxes within the broad inequalities found in this study. Sylhet is the home of most Bangladeshis that migrate to other countries, mostly to the United Kingdom of Great Britain and Northern Ireland. This administrative division receives a major flow of foreign currency from nonresident Bangladeshis: in 2005, 16% of households in Sylhet received remittances, compared with less than 5% of households in Rajshahi, Khulna and Barisal. Previous research in Bangladesh has shown that the poverty rate among households receiving remittances from abroad is 17%, compared with 42% among the rest.¹² Like many other developing countries, most surveys indicate that in Bangladesh the majority of remittances are used for consumption of food and clothing, and national food-security data have also placed Sylhet as a relatively food-secure region;²⁵ it is therefore startling that the region has the poorest nutritional status.

However, Sylhet is also reported to be a poor-performing region for other social indicators. According to the Bangladesh Bureau of Statistics,²⁵ the overall literacy rate in Sylhet division was the lowest in the country, at 39.2% in 2007, with an even lower female literacy rate of 35.1%. Sylhet has the highest mortality rates for all-mortality indicators (for example, neonatal mortality, postneonatal mortality and infant mortality) except child mortality.²⁶ Moreover, this division has a much lower demand for family planning and, as a result, registered a lower contraceptive prevalence rate and higher total fertility rate than other divisions.¹³

It has been reported that, although remittances have brought improvement in overall earnings in households in Sylhet, they are seen mostly as important financial means for housing and land purchase. Investment in education, business or traditional productive uses, and in savings, was reported to be

rather small.²⁷ As such, amid economic improvement, social indicators have lagged behind in this area when compared with national standards.

A recent report by Save the Children²⁸ predicted that the stunting rate in 2030 would be 25%, if the trend from 1997 to 2011 continued to 2030; this is four percentage points higher than the target set by the Sustainable Development Goals (SDGs) for 2025. The report assumed that only the top 10% richest by wealth of the population will meet the target of halving the rate of stunting. The Khulna administrative division is also likely to get close to this target. However, the Sylhet division, the poorest quintile, and urban areas of Bangladesh, will remain some distance from the target if current trends continue. The current study concurred with these findings.

Although there has been overall development during the past four decades, Bangladesh has also experienced marginalization and social exclusion. Inequality in social and economic outcomes exists among the geographic regions. Haors and tea estates were two significantly different geographical locations in Sylhet where housing, transportation and livelihoods were significantly worse than in other parts of the administrative division and the country. Seasonal variations have also been reported in Sylhet.²⁹ Overall, life in these areas was poor and risky. Economic deprivation due to geographical difference and isolation has created social inequality. The children in these areas are unable to undergo continuous education, mainly owing to economic deprivation and social inequalities arising from their geographical isolation.

Limitations of this study included lack of information on consumption of energy intake and macro and micronutrients, and physical activity, which are important components in estimating nutritional status. The cross-sectional nature of the surveys does not allow causal inferences to be drawn. Information on, for example, childcare practices, food taboos and management of illness was not collected.

Conclusion

There can be no doubt that special, focused efforts must be made in the Sylhet administrative division of the country if the overall performance of the health, nutrition and population sector is to reach the targets set by SDG 2 of zero hunger and ending all forms of malnutrition. A recent report by Save the Children commented that Bangladesh has done well in reducing chronic malnutrition relative to other countries, but progress still needs to accelerate to meet targets, and looking below country level has revealed that, in particular groups, there are still sizeable numbers of children who need to progress at a faster rate.²⁸ More in-depth data collection by breaking down the divisions into smaller administrative units (that is, upazila/union/village) is recommended to identify the worst-performing areas and the interventions needed. A holistic approach to development is required to improve the situation in these areas. Considering the variations among the administrative divisions, a needs-based household-centric integrated development approach may be suitable for addressing marginalization and exclusion.

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Exploring the factors that influence the perceptions of disability: a qualitative study of mothers of children with disabilities at a community-based rehabilitation centre in Sri Lanka

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ABSTRACT

Background: The prevalence of disability is growing worldwide; however, perceptions regarding disability are not well understood. The aim of this study was to explore factors that influence the perception of disability among mothers of children with disabilities who were attending a community-based rehabilitation facility in Sri Lanka.

Methods: A descriptive qualitative research design was employed. Thirteen semi-structured interviews were conducted with participants receiving rehabilitation services at a community-based facility. Interviews were recorded, transcribed and coded using software for qualitative data.

Results: Three major themes emerged from the analysis: (i) level of family and community support; (ii) spiritual and cultural interpretations of disability; and (iii) outcomes of rehabilitation services. Perceptions of disability appeared to be strongly influenced by the social, community and spiritual/cultural support structure in which the mothers lived. In particular, the support from the participant's spouse emerged as a primary factor exerting strong influence on perception, and future outlook, among the participants. Engagement in community-based rehabilitation programming also reinforced positive perceptions, created a sense of hope among participants regarding their child's future, and established aspirations for future education and employment opportunities alongside social integration.

Conclusion: Knowledge of factors that influence the perception of disability can inform future implementation of public-health and community-based initiatives, and may improve social integration of children with disabilities in lower-resource settings.

Key words: children, community-based rehabilitation, disability

BACKGROUND

The concept of “disability”, and what it means to live with a disability, is multifaceted because of the richness of public interpretation and personal meaning. The World Health Organization (WHO) defines disability as “... a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives”.¹ While this operational definition may provide a valuable framework for describing an individual's physical

impairments, activity limitations and participation restrictions as outlined by the International Classification of Functioning, Disability and Health,² it may not capture the depth and breadth of the interactions between political, environmental and social barriers that many people with disabilities regularly encounter.³⁻⁵ In 2008, the United Nations Charter on the Rights of Persons with Disabilities (“The Charter”) established a foundation for international public policy regarding the inclusion of people with disabilities in all aspects of social, political, cultural and economic life, as part of their individual

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and collective human rights.⁶⁻⁸ The Charter recognized that people with disabilities must have equal access to sociopolitical infrastructure compared with members of the population who live without a disability, across the landscape of high-, middle- and low-resource countries. However, linking international public policy such as The Charter with local and community action can be challenging for a variety of reasons, including economic scarcity, societal priorities and public perceptions.⁹⁻¹¹ The Charter is intended to “level the playing field” in the quest for equal human rights for all people, regardless of the level of functional abilities, or the communities or country in which a person lives. Although 160 countries are signatories to The Charter, there remains a large gap in terms of equal opportunities and status for persons around the world who live with a disability.⁶

In 2011, WHO, in conjunction with the World Bank Group, published the first ever *World report on disability*, a compendium of what is known about disability and where significant gaps in knowledge persist.¹² This report described that there are now over one billion people worldwide who live with some form of disability, and that this point estimate represents a 5% increase from the previous decade.¹² Despite the relatively high prevalence, only 2% of the estimated one billion individuals with disabilities have access to features of basic human rights, such as security, education and access to care,^{13,14} including 93 million children worldwide between the ages of 0 and 14 years that experience a moderate to severe disability. Children with disabilities (CWDs) are often unable to achieve an independent and productive lifestyle when compared with other children who may not have a disability.^{15,16} Hence, the extent to which a person with a disability, and particularly a CWD, can achieve the goals of equal human rights as set out by The Charter may be particular arduous in lower-resource communities, where economic scarcity, food insecurity and poverty often occupy the public policy agenda.

Sri Lanka is categorized as a lower-middle-income country in south Asia, with a gross national income of approximately US\$ 9500 per capita.^{17,18} The 2011 Sri Lankan Census declared that 1.7% of the population of about 20 million people had a functional disability.¹⁹ Given that the *World report on disability* estimated that 15% of a population has a disability,¹² the published estimate of less than 2% is likely to be an underestimation of the actual number of people with disabilities in Sri Lanka. In general, Sri Lankan women devote a significant portion of their lives as caregivers for their children,^{20,21} by extension, it has been noted that mothers of CWDs are often the primary decision-makers with regard to their CWDs, and hence understanding the perceptions of disability among mothers may have an influence on the health and rehabilitation decisions that are made on behalf of CWDs.^{22,23} Although there has been some research regarding the perception of disability among mothers of CWDs in other countries,²²⁻²⁶ to the authors’ knowledge, there are no studies that have explored the perception of disabilities among Sri Lankan mothers with CWDs. The purpose of this study was thus to explore factors that influence the perception of disability among mothers of CWDs who were receiving services for their children at a community-based rehabilitation facility in Sri Lanka. The aim of the study was to explore the experiences of these mothers,

and not necessarily to yield generalizable knowledge that is directly applicable to other settings. This work was also embedded within an ongoing effort to build local capacity and expertise in qualitative research skills.

METHODS

A descriptive qualitative design was employed during this research study. Approval for the study was obtained from the research ethics committees of Duke University, Durham, North Carolina, United States of America (USA), and Ruhuna University Hospital, Galle, Sri Lanka. The location of the study was a community-based rehabilitation facility – “the centre” – located in southern Sri Lanka, which offers a large array of services ranging from medical assessments and rehabilitation therapy, to social activities and peer-support networks. This study was based on interviews and, although conducting such interviews in the local language is most appropriate, this was not feasible in this instance. Since this was the first study at this site, investigators complied with the request of the local research partner that interviews should be conducted in English and translated as described below. This followed the approach of a similar study done by Maloni et al. in Bangladesh.²³

Identification and recruitment of participants

Convenience sampling was used for this study. Potential participants were included if they (i) had a CWD receiving services at the centre; and (ii) were willing and able to participate in a one-on-one interview during the study time frame. A staff member not involved in patient care recruited mothers who met the inclusion criteria to attend project-information sessions held at the centre. This information session was led by the senior author, and potential participants were informed about the goals of the study and the methods (i.e. that the interviews were to be conducted in English). They were also informed that participation was completely voluntary, that all information would remain confidential, and that they would be free to withdraw at any time without consequence. A total of 13 participants expressed interest in the study and provided their consent to participate, and all completed the study. Owing to the time frame of the study, it focused specifically on the experiences and perceptions of mothers who had already decided to seek rehabilitative care for their CWD. Further exploration of the perceptions of mothers of CWDs not seeking rehabilitative care is an area that requires further investigation.

Qualitative data were collected through semi-structured face-to-face interviews in English, which was then synchronously translated into Sinhalese, the local language of the participants. Participant responses were then translated from Sinhalese back to English. The interviews consisted of open and close-ended questions (see Box 1).

The interviews were conducted by one investigator. The translator was the senior investigator on the study, a paediatrician, and a faculty member at Ruhuna University Hospital, Galle, Sri Lanka. Her interest in the question of perception of disability stems from the point of view of a

Box 1: Interview schedule

Section 1:

“The first set of questions is about you, your family and your children.”

1. What is your name?
2. What is your age?
3. How many children do you have?
4. Do you have any other children with disabilities?
5. How far from the centre do you live?
6. How often do you attend the centre with your child?

Section 2:

“The next set of questions is more about your child and their disability.”

1. How did you find out about your child’s disability?
2. When did you find out that your child had a disability? Who informed you?
3. Do you know the name of the medical term of the disability your child has?
4. How did you feel when you found out that your child had a disability?
5. How has your role changed since [child’s name] has come into your life?
6. How does religion impact how you feel about your child’s disability?
7. What do you believe caused the disability in your child?
8. What does disability mean to you?
9. How does your community view disability?
10. How does your community view your child’s disability?
11. How does the rest of your family view your child’s disability?
12. Do you have support from your family or the community?

Section 3:

“The last set of questions is about the rehabilitation services and your child.”

1. What made you decide to pursue rehabilitation treatment for your child?
2. How did you hear about the centre?
3. What are the other treatments (medical/non-medical) you have used to treat your child?

local health-care provider actively involved in the day-to-day direct care of patients and families, alongside an interest in the exploration of mechanisms to improve outcomes at the population health level. She was not directly or indirectly involved in the care of any of the children or families who participated in this study. All 13 interviews were conducted during the months of March and April of 2012 at the centre, and all were audio recorded and transcribed verbatim by a second translator, who was an external consultant not involved in this research. All transcribed interviews were then reviewed and matched for accuracy against the audio recording, by

members of the research team. The duration of the interviews ranged from 30 minutes to 55 minutes and, at the request of the community-based facility, no direct incentives were provided for mothers participating in the study, although light snacks and water were available during the interview. It is acknowledged that language, and the process of translation from Sinhalese to English, then back to Sinhalese, presented a challenge during this study. All efforts were made to clarify ambiguities, and, given that the all interviews were conducted by the same research team members, there was a degree of consistency in the process.

The confidentiality of participants was maintained at all times, as required by the ethics review committees at Duke University and Ruhuna University. Confidentiality was maintained in the following ways: (i) only the participant and two researchers were present during the interviews; (ii) each participant was provided a de-identified number and no names were mentioned on any documents or audio recordings; and (iii) only aggregated data were used in final reporting, which includes this paper.

Data analysis

The transcribed interview data were entered into a software package for qualitative data analysis (NVivo 2.01, Sage Publications Ltd, California, USA), for systematic coding. Consistent with the qualitative content analysis approach, the research team then performed qualitative content analysis using the English translated interviews, in order to identify themes that emerged from collective perceptions and experiences shared by the participants during the key informant interviews.^{27,28} Qualitative content analysis has been reported to be useful when the description of phenomena is desired, and has been used in similar research studies.²³⁻²⁶ Each member of the research team began by reading all of the transcripts independently, and then met regularly to review and discuss each of the interviews. The discussion of the content of the interviews resulted in the development of a large set of overarching concepts, and the research team consolidated and

arranged these concepts into codes. Once all the codes were generated within the interview data, the research team reviewed the codes and discussed any discrepancies and the extent to which the codes were related to each other. Once a set of codes was agreed upon, two members of the researchers coded each of the 13 interviews. Once the coding of the interviews had been performed, two other members of the research team re-coded all of the interviews, and then compared the results of the coding. A few codes were consistently found to be coded differently between the two investigators; however, after discussions among the investigators, there was an agreement and the issue was resolved by merging the codes. Once the coding process was completed, the research team then met and discussed the codes, and decided on the main themes that were related to the guiding research objectives. The identified themes were based on collective perceptions and experiences shared by the participants.

RESULTS

A total of 13 participants, between the ages 32 and 53 years, participated in this study. Among the participants, six identified their child's specific diagnosis as "Down syndrome", while one reported a general diagnosis of "seizures and tuberculosis". The remaining six participants could not report a specific diagnosis (see Table 1). Given that the purpose of this study was to explore factors influencing the perception of disability,

Table 1: Participant demographics

Participant number	Age of mother (years)	Mother's description, definition or diagnosis of disability	Sex of child with disability	Age of child with disability (years)	Total number of children in the family unit
1	53	The child has a lot of problems remembering things, there is no communication	F	9	3
2	33	The child was not walking, was very angry and aggressive	F	6	2
3	39	Seizures, does not write or talk like other people, there's a speech impairment	M	11	3
4	45	Down syndrome	M	2.5	2
5	52	Slow to learn; developmental delay, child's milestones are delayed	M	14	2
6	44	Down syndrome	M	11.5	2
7	n/a	Down syndrome	M	n/a	3
8	50	Intellectual impairment; delay in achieving developmental milestones	M	17	2
9	n/a	Down syndrome	M	14	2
10	39	Down syndrome	M	5	2
11	32	Seizures and tuberculosis	M	1	2
12	39	Child may walk, has a protruding tongue, and will be short in stature according to physician	F	3	1
13	39	Down syndrome	M	2	3

n/a: not available.

and not the perception of a specific diagnosis, the research team did not seek clarification of the ambiguous descriptions of diagnosis. It is acknowledged that there may be variances in mothers' perceptions when a child has differing qualities and abilities but this was not a focus for this study; however, it does represent an area for future essential research.

Based on the analysis from this study, three major themes emerged regarding factors that seem to influence perceptions: (i) level of family and community support; (ii) spiritual and cultural interpretations of disability; and (iii) outcomes of rehabilitation services. Collectively, these three themes appeared to exert strong influence over the participants' perceptions of disability.

Theme 1: Level of family and community support

The level of family and community support received appeared to be an important factor that influenced overall perception. Most of the mothers who participated in this study expressed some level of family support, although the level of support was variable. Mothers who reported both emotional support and logistic help with care for their CWD from their immediate and extended family seemed to perceive disability more positively. In this study, the term "positive" is used to indicate that the participants expressed some level of acceptance of their child's disability and/or felt that it was possible for the child to improve their level of function. This may be an important distinction from a possible biomedical interpretation of "positive", which may suggest that mothers felt that the disability could be cured or resolved. Throughout this study, the use of the term "positive" implies the former.

The participants shared that there was variation regarding the roles that the father played in the life of their CWD. All of the participants were married and living with their spouse at the time of the study, and some mothers stated their spouse was supportive of the child immediately after understanding the extent and implication of a lifelong disability. Other mothers reported that their husbands were initially emotionally distant, but eventually came to love and be supportive of the child. A small minority of the participants, however, indicated that their spouse was completely non-supportive of the child, and that this lack of support had an important and long-lasting negative emotional effect on the mother. In this study, the term "negative" is used to indicate a sense of despair for the future, and limited hopes and aspirations for the child's future. As one mother described:

... I think it's because all his [the father] dreams are shattered that he won't care for the child. He even wanted to destroy the child, even ... and he doesn't like the child to be taken out, he wants the child to be kept in the home .

While only a few participant opinions were reflective of the statement above, the lack of support of a spouse seemed to emerge as insurmountable for the mothers who participated in this study. This finding is in contrast to the alternative scenario, where strong spousal emotional support was described as a tremendously important and positive aspect of overall support of the mother. It appeared that all other factors of family support

were secondary to spousal support for the child in terms of a mother's perception of disability.

A frequently described source of additional emotional pressure for all participants was the influence of the husband's family. There were several instances where participants indicated that their husband's family viewed the CWD as a source of negative stigma for the entire family, to the extent that some wanted to hide the child within their home and community. Although extended family pressure was perceived to exert great anxiety on the participants, one participant suggested that an advocate internal to the family could have great influence over the perceptions of others. For example, one participant described the benefits of having someone within the family to advocate for the child's acceptance, in the following way:

In the beginning, there were the problems from ... the in-laws. They were saying that this is a sin to have a child in the family, having to look at him. So, initially there were negative reactions from ... the in-laws. My family of course, was very supportive because we had an uncle who is an obstetrician ... who explained to the others about the child's condition. They [the in-laws] were then more accepting of the child. But after a while, their attitudes changed [towards being more accepting of the child].

Very few mothers felt the local community was at all supportive of their children. However, among a few mothers, community support served to positively influence the mothers' perceptions of disability. As described by one respondent:

And then, there was a friend of mine... [he] also encouraged me to take the child out, saying that, if the child is exposed to this new experience 10 times, [the child] will learn at least one thing. So, that helped me a lot to bring the child out. Also, the child is now getting on very well with the neighbours, everybody loves [the child] and everybody is very supportive.

It may be important to underscore that the above sentiment was not widespread among the participants, and the majority felt the community maintained that a CWD was overall a "bad omen" that stigmatized the community. Participants also recounted that some community members openly and consistently stated that the CWDs should not be encouraged go to school, play sports, get married, have a family, or even use public transportation. Overall, the participants described varying levels of support for their CWDs from their families and the community; nevertheless, support of immediate family and spouse appeared to influence the perception of disability. Overall, it appears that the perceived support of a spouse, then family, and then community are important; but the support of the husband and father of the child appeared to exert the greatest positive influence on the participants.

Theme 2: Spiritual and cultural interpretations of disability

All of the participants identified themselves as culturally Sinhalese and, like many Sri Lankans living in the south of the country, all were all practising Buddhists. Spiritual and

cultural interpretations of disability, as either the cause of their child's disability or the reason for improvement/worsening in the function of the child, were widespread among the participants. When asked about the cause of their child's disability, most participants suggested that the child was given a disability because of a sin of the child, mother or father in a past lifetime. One mother described a possible reason for her child's disability as being related to the fact that she looked at people with disabilities while she was pregnant. She described this experience in the following way:

I have a brother who has a disabled child. The child has cerebral palsy because the child can't see or move his limbs ... he is just bedridden. So, I didn't know I was pregnant initially so I went to see this child very often. ... So, I think maybe that would have had a bad effect on my pregnancy .

In addition to viewing spiritual and cultural underpinnings as a causal factor in acquiring a disability, the majority of the mothers also relied on religious (or in the specific case of all the mothers in this study, Buddhist) practices, such as prayer, as treatment for the child. One mother stated:

We go to the temple and make him listen to the Buddhist chanting called Puja, which is supposed to be a kind of blessing for the child.... So, I let the child listen to those things. And the other thing, I have tried some traditional methods, also, like making the child wear a protecting charm, an amulet, something like that ...

A few participants also reported that religious practices were important ways that the mother used to cope with the fact that their child was born with a disability, providing them with spiritual hope for the future and allowing them to better manage their child's disability. Given that spirituality and religion were described as both a cause and a potential treatment of disability, it may be important to note that participants in this study also appeared to ascribe equal importance to both medical rehabilitation treatments and spiritual and religious practices. Half of the participants either explicitly or implicitly vocalized this duality and the tension between a fatalistic perspective of disability being controlled by a higher power and wanting the child to receive rehabilitation to actively improve their abilities. The following discussion illustrates this point:

It's mental, the planetary things. My belief in those things, it soothes me I think, knowing that the Saturn will return ... I have that in my mind but I am still willing to continue with the therapy .

Overall, spirituality and culture appeared to play an important role in the lives of the mothers and the children. The roles of spirituality/religion alongside rehabilitation services, were perceived to be important factors that affected their perception of disability, albeit from different viewpoints.

Theme 3: Outcomes of rehabilitation services

Access to and outcomes of rehabilitation services was a third theme that participants reported generated positive perception of their CWDs. The participants who witnessed tangible

improvements in their child's physical functional level during or after rehabilitation also expressed more positive perspectives regarding their child. Some of the participants reported a positive effect on their emotional status when they could see or witness improvements in their child with rehabilitation, even when these improvements were short lasting.

Witnessing the tangible outcomes of rehabilitation was placed in very high regard, because participants frequently reported that rehabilitation services eased their worries about their child's disability. After receiving services and becoming familiar with rehabilitation, some participants felt "less worried" and "they realized that physiotherapy helps a lot to improve the child's condition". For instance, as recounted by one participant:

Initially, the child couldn't do anything but now the child can walk after physiotherapy. But he had this speech impairment, so after that he was brought to XXX and after the speech therapy, even the speech got better .

Another commonly reported aspect was the notion that continued access to services would lead to more improvements in the future. As one mother stated:

The physiotherapist, he is like God to me because he allowed the child to do so many things. He taught me how I can help the child to sit. So, now the child is doing it on his own. So, I am sure that he will be able to walk and that's what I want to see, as soon as possible, to see the child walking .

Participants described feeling much less scared when they witness functional improvement, and were seemingly more able to cope with their child's disability. One participant suggested that having exposure to informal peer-support networks obtained through rehabilitation was an important factor for her and her family. She recounts:

I was initially scared because I was scared that the child wouldn't become normal again. But then, when I saw that there are other children with the same disabilities in the hospital, I was less worried. And then, afterwards, I got to know about physiotherapy. And [when] the child was put in the physiotherapy room, I felt that the child could be developed. She [the physiotherapist] showed some improvement in development in the child. So, I [was] less worried [about my child] .

When participants had more positive levels of perceptions, they also seemed more likely to contextualize goals for their children in concepts such as accessing education and obtaining sustainable employment. A consistent concern was the emotional and economic well-being of the child beyond the parents' lifespan; as such, participants described economic self-sufficiency and employment as critical to securing a stable future. For instance, as one participants put it:

I expect the child to stand on his own two feet, to be independent, to learn some craft, because even though there is a sister, we cannot be sure ... whether the sister will look after him or not. So, I want him to be independent, to learn some craft so that he can make his own living ... and maybe attending this centre can help ...

Another common hope for mothers was that their children would one day become “normal”. The meaning of “normal” varied significantly among the participants, from being able to write and walk, to securing gainful employment. This move towards so-called normality was not, however, to suggest that the CWD would be cured of their condition or disability, but rather that he or she would be able to perform the roles and responsibilities as a member of society in their unique fashion. A conflicting view was identified when asked if marriage was a possibility for their child in the future. Several mothers dismissed the idea as highly unlikely, and only one mother discussed the possibility of marriage between her child and another child with disability:

When I took him [her child with disability] to a function [social event], there was another organization that provides similar services like this, and she [another child with disability] is going there also. I met another person who told me that a person known to him, a Down’s person, married another Down’s person. So, in future, sometimes there is the possibility, but I am not very hopeful ... we can’t say about the future, this moment .

Mothers with more positive perspectives on disability also expressed hope for acceptance and integration of their CWD in society, with equal opportunities in the areas of education and employment based on their capabilities. Mothers believed that creating such opportunities would not only benefit their children, but also serve as a message that those with disabilities have a right to a place within society. As expressed by one mother:

The change should start from the schools, they have to show the others [children without disabilities] that these children [CWDs] are part of the society and they feel and sometimes they think like others. So, they should not be discriminated, they should give equal opportunities like other children, to make the other children understand that they are also part of the society. So, it starts from the schools, it will go and catch on. Society should change their attitudes and the people in the immediate surrounding should also make them aware. And after a few generations, generations change, sometimes the attitude might be changed .

DISCUSSION

This investigation sought to explore factors that influence the perception of disability among mothers of CWDs already receiving care in a community-based facility. This study has reported that the family, community, spirituality/culture and outcomes of rehabilitation can exert a positive influence on perception, and it has highlighted that the influence of the spouse is a particularly important factor. Some participants regularly faced an internal struggle when family members, especially their husbands and extended family, had a negative view towards their CWD. However, when their spouse, members of their family and community demonstrated support of the CWD, there seemed to be a more positive perception by the mother towards the child, and a greater likelihood of contextualization of goals well beyond impairments, and into maximizing social integration for their CWD.

In practical terms, it may be important to examine and understand the degree to which any one influencing factor might be most important to an individual mother, or even to a community of mothers, at any given moment. Given the study design, while it was not possible to determine that there was a critical time order or sequence of when one influencing factor might be more important than another across the life-course trajectory of a CWD, it stands to reason that there may be moments when particular factors are more important than others. We propose, for instance, that the influence of spousal support might peak at the time when a diagnosis or determination of a disability is made, and that, over time, the family and community support factors might then take their turn as primary factors. Although further research is warranted, assuming positive influence on perception is desirable, it might be important therefore to consider the timeline of events, or life-course of the child. We postulate that when an influencing factor is not present at the right time and place, a mother might seek support elsewhere, and this may be where access to a medical, social, rehabilitative or public-health infrastructure becomes a critical substructure to replacing the support that would be preferably obtained elsewhere. It may be reasonable to also ask whether a community-based rehabilitation centre can effectively act as a temporary proxy for family and community support.

Moreover, given that this study has highlighted that spousal support emerged as a primary influencing factor, it is interesting to consider whether community-based facilities that influence perceptions by creating specific and targeted awareness programmes, or peer-support networks, to more fully engage the fathers of CWDs early in the process, would affect the perceptions of the mothers and ultimate societal integration for their CWDs. Raman et al.,²⁴ Daudji et al.,²⁵ and Ahmed et al.²⁹ have suggested it is important for health-care providers to educate both the family and community about CWDs and to organize social support for these children; and Parker et al.³⁰ and Juneja et al.³¹ have also suggested that the family unit exerts strong influence and control over health-seeking behaviours. However, given the present findings, it may be that a missing link in the advocacy strategy is education and support for the father, who, in turn, might exert an influence on overall perception in a setting like rural Sri Lanka. Although the present data do not allow these questions to be answered with any certainty, this represents a next step in our research process.

Limitations

This study set out to explore the perceptions of disability among mothers of CWDs in Sri Lanka. There were limitations to the study; firstly, the sample of participants included in the study were those individuals who were already accessing care at a community-based rehabilitation facility, and they may have already been generally supportive of the rehabilitation process. Secondly, the interview was conducted in English, which was then translated to Sinhalese, and participant answers were initially in Sinhalese, and then translated to English. There are always challenges in interpreting meaning and intentions during multiple translations, but to the extent possible, this

was minimized through asking for clarifications when required during the interviews, in order to understand the meaning of what was said by the participant. At times, this required the participant to re-state their commentary, and at other times it meant that the translator re-stated their interpretation of what the participants said when it was not clear to the researchers.

Conclusion

Several complex and interrelated factors appear to contribute to perceptions of disability. When participants seemed to have perceived high levels of support (especially from their spouse), they also seemed to have greater positive perspectives or perceptions regarding disability, which, as reported in this study, leads to goal-setting beyond physical improvement and into areas such as social integration and education. This study may provide perspectives regarding the necessity to implement rehabilitation programmes that are inclusive of broad and multidimensional strategies that not only facilitate physical rehabilitation, but also incorporate the family and community. Given the findings of this study, such programming could lead to improved functional outcomes, but, equally notably, to outcomes related to achieving improved independence and social participation in the community. Knowledge of factors that influence the perception of disability can inform future implementation of public-health and community-based initiatives, and may improve social integration of CWDs in lower-resource settings. Overall, these findings underscore the importance of creating patient- and family-oriented, community-based, and participatory approaches to health and rehabilitation services, as part of a process to facilitate the laudable goals of equal human rights as set out by the United Nations Charter on the Right of Persons with Disabilities.⁶

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Tobacco-promotional activities in rural Sri Lanka: a cross-sectional study of knowledge, exposure and responses among adolescent schoolchildren

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ABSTRACT

Background: Tobacco promotions are linked to tobacco consumption in adolescents. The aim of this study was to determine knowledge of and exposure and responses to tobacco-promotional activities and factors associated with knowledge among adolescents in a rural setting in Sri Lanka.

Methods: Seven schools in Polonnaruwa district were randomly selected for this cross-sectional study. Adolescents ($n = 500$) aged 14–15 years in grade 10 were selected using convenience sampling and studied by using a self-administered questionnaire during June–October 2014. The questions on exposure to tobacco-promotional activities were based on the validated questionnaire of the Global Youth Tobacco Survey. Adolescents were categorized into two levels of knowledge, exposure and responses to tobacco promotions, based on the scores obtained. Selected factors associated with knowledge of tobacco promotions were assessed using univariate and multivariate analyses.

Results: The response rate was 99.6% (498/500). The mean age of the adolescents was 14.9 years (standard deviation ± 0.37) and the proportion of females was slightly higher ($n = 280$, 56.2%) than for males. The prevalence of current smoking was 3.2% ($n = 16$). Half (48.6%, $n = 242$) of the adolescents had a good level of knowledge of tobacco-promotional activities. Most (64.9%, $n = 323$) had experienced a low level of exposure to tobacco-promotional activities, while 85.7% ($n = 427$) indicated that they had responded/would respond assertively to exposure to tobacco promotion. In the univariate analysis, having a mother with a high level of education (odds ratio [OR] 1.742), having a father with a high level of education (OR 1.997) and the student attending a type 1AB school (OR 1.310) were significant factors associated with a good level of knowledge of tobacco-promotional activities. A father with a high level of education (adjusted OR 1.772) and the student attending a type 1AB school (adjusted OR 1.455) were the factors associated with a good level of knowledge for tobacco-promotional activities, when confounding effects of the variables were taken into consideration.

Conclusion: Knowledge of tobacco-promotional activities was poor among the adolescents in the rural setting in Sri Lanka. Nevertheless, most of the adolescents in the study population indicated that their responses to such exposures were/would be assertive.

Key words: adolescent, tobacco, tobacco promotion, Sri Lanka

BACKGROUND

Tobacco promotions are linked with adolescent tobacco consumption.¹ The 2005 World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC) imposed

a ban on direct or indirect commercial communication, recommendation or action promoting a tobacco product/tobacco use.² However, the tobacco industry uses stealth-marketing strategies to attract new adolescent tobacco users.^{3,4} Provision of free samples and incentives, brand extensions

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and offering sponsorships are some of these strategies.^{1,5-6} Sri Lanka enacted the National Authority on Tobacco and Alcohol (NATA) Act No. 27 in 2006, following ratification of the FCTC.⁷

The latest national estimates of prevalence of adult smoking in Sri Lanka are from the STEPwise approach to Surveys (STEPS) survey in 2006.⁸ That survey was conducted in five randomly selected districts of the 25 districts in the country, among 12 401 adults aged 15–64 years (6140 males and 6261 females). The survey revealed a prevalence of current smoking (having smoked tobacco at any time during the past 30 days) of 15% among adults, with prevalences among males and females of 29.8% and 0.4%, respectively.

In 2003, 2007 and 2011, Sri Lanka took part in the Global Youth Tobacco Survey (GYTS), which provides internationally comparable information related to tobacco use among youth aged 13–15 years.⁹ The latest GYTS in 2011¹⁰ was conducted among a nationally representative sample of 4963 eligible students in grades 9–11, of which 4031 were aged 13–15 years. The survey estimated the number of current tobacco smokers, defined as having smoked tobacco at any time during the past 30 days, to be 3.9% among all adolescents, with a prevalence of 5.5% among boys and 2.2% among girls. The percentage of current users of smokeless tobacco (that is, had used smokeless tobacco at any time during the past 30 days) was 8.5% (boys 13.0%, girls 4.1%). Combining these two indicators together, the GYTS in Sri Lanka in 2011 estimated that 10.5% were current users of tobacco (that is, had smoked tobacco and/or used smokeless tobacco at any time during the past 30 days), with corresponding estimates for boys being 15.7% and girls being 5.4%. Compared with the 2007 GYTS, which indicated that current tobacco use was 9.1%, the more recent results represented a slight increase in current tobacco use among adolescents. When compared with other countries of the South-East Asia Region, tobacco use among Sri Lankan adolescents was found to be low, and higher only than tobacco use among adolescents in Bangladesh.⁹

The GYTS also assessed the influence of tobacco in the media on adolescents.¹⁰ Of the study population, 62.1% (59.7% among boys and 64.1% among girls) had noticed tobacco advertisements in newspapers or magazines in the past 30 days, and 2.9% (4.2% among boys and 1.8% among girls) had been offered a free cigarette from a tobacco company representative. The proportion of adolescents who owned an item displaying a cigarette brand logo was 4.6% (5.7% among boys and 3.5% among girls). The great majority of adolescents (82.6%) had also noticed anti-tobacco messages in the media during the past 30 days, with the corresponding proportions among boys and girls being 83.1% and 82.2%, respectively.

Another source of evidence of the exposure of adolescents to tobacco-promotional activities through the media was a recent case-control study conducted in an urban setting in Anuradhapura Divisional Secretariat in Sri Lanka.¹¹ The aim of that study was to assess the effectiveness of tobacco-control measures on behaviour changes related to tobacco use among adolescents and young adults. Cases (current quitters) and controls (current smokers) were compared, to ascertain the effectiveness of the tobacco-control measures

implemented by NATA to bring about the behaviour change of quitting. Information was gathered using a self-administered questionnaire and focus group discussions. The study included a total of 198, with 66 (27.3% adolescents and 72.7% young adults) quitters and 132 current smokers (18.2% adolescents and 81.8% young adults). Univariate analysis of the data revealed that 95.5% of cases and 87.9% of controls had noticed anti-smoking messages in the media during the 6 months preceding the study ($P < 0.001$). Exposure to anti-smoking media messages on television was more effective in motivating smokers to quit (odds ratio [OR] 0.54, 95% confidence interval [CI] 0.14–1.87) than exposure to messages on radio (OR 1.22, 95% CI 0.46–3.25). Assessing exposure to the tobacco-promotion messages in the media, a majority (66%) of cases and controls did not report exposure to tobacco-promotion advertisements, while the numbers who had never seen tobacco advertisements during community events were 47% and 50% among the cases and the controls, respectively. That study also reported that all cases ($n = 66$), as well as 89% ($n = 118$) of the controls, had not noticed competitions or prizes sponsored by the tobacco industry during the past year. The study concluded that the tobacco-control measures implemented by NATA had had a favourable impact on motivating people to quit tobacco use, and that television was the strongest media source for information on the ill-effects of tobacco use.

Against this background, the present study aimed to describe the knowledge of and exposure and responses to activities promoting tobacco use among adolescents in a rural setting in Sri Lanka, and to assess factors associated with knowledge of activities promoting tobacco use.

METHODS

This was a descriptive cross-sectional study of students in three randomly selected type 1C schools and four type 1AB schools in the educational division of Thamankaduwa in Polonnaruwa District. Polonnaruwa District is one of the 25 districts in the country and one of the two districts of the North Central Province of Sri Lanka. Typing of schools in Sri Lanka is based on the different age groups that they teach, and types 1AB and 1C are schools that teach adolescents of the age group selected for this study.

The study unit was an adolescent in grade 10, and the study aimed to recruit a sample of 500. There were four type 1AB schools and six type 1C schools in Thamankaduwa. For logistic feasibility of the study, it was decided to conduct the study in adolescents from 7 of the 10 schools: the four type 1AB schools, and three randomly selected type 1C schools. The number of students to be included in the study was 300 from type 1AB schools and 200 from type 1C schools, based on the ratio of the approximate numbers of students in the relevant age group in each type of school. The number of students selected from each school within each type of school was more or less equal. The study was conducted during June–October 2014.

A pretested self-administered questionnaire consisting of mostly closed-ended multiple choice questions was used to collect the data. The initial section of the questionnaire

contained questions relating to selected sociodemographic characteristics such as sex, parents' highest education level and whether the adolescent was involved in extracurricular activities, including whether he/she was a leader in clubs/groups in school.

The current status of smoking of the adolescent was investigated using the validated question of the GYTS:¹⁰ "During the past 30 days (1 month), on how many days did you smoke cigarettes?"

The questions on knowledge of tobacco-promotional activities were based on tobacco-control laws in Sri Lanka and promotion strategies used by the tobacco industry. Assessment of exposure to tobacco-promotional activities was based on seven questions; several of these questions were the same as those in the GYTS, while others were slightly adapted versions of the questions in the GYTS. Exposure to pro-tobacco advertising and promotion, either directly or indirectly through the media, was ascertained by using questions from the GYTS: "During the past 30 days (1 month), how many advertisements for cigarettes have you seen on billboards?" and "During the past 30 days (1 month), how many advertisements or promotions for cigarettes have you seen in newspapers or magazines?". Furthermore, other questions from the GYTS, "Do you have something (T-shirt, pen backpack, etc.) with a cigarette brand logo on it?" and "Has a cigarette company representative ever offered you a free cigarette?", were also used in the present study to assess the response. Many measures were taken to minimize nonresponse and to ensure honest responses. The confidentiality of the information was guaranteed by not asking for the names of the students or the schools of the study participants. It was ensured that the school teachers were not present at the data-collection sessions. Students were made to sit apart from each other, to make sure that the answers were not shared. The principal investigator was present throughout the data-collection period to answer any queries of individual students regarding the questionnaire.

Informed written consent was obtained from parents and assent was obtained from the students prior to administering the questionnaire. Ethical clearance was obtained from the ethics review committee of the Faculty of Medicine, University of Kelaniya, Sri Lanka.

In assessing the responses of adolescents to tobacco-promotional activities, the students who had previously been offered free cigarettes by someone working for a cigarette company or who had been offered gifts displaying a tobacco logo were asked about the way/ways in which they had responded. Those who had not experienced these situations were requested to indicate the likely way/ways in which they would respond. The students were also asked whether they had carried out any activities in school against tobacco promotion.

In the analysis, the questions on knowledge of activities promoting tobacco were awarded one mark each if the responses were accurate, while each inaccurate response was awarded a zero mark. The maximum score was 15 and the minimum score was 0. A score of 8 or more was used to categorize the adolescents as having a "good" level of knowledge of activities promoting tobacco, while a score of less than 8 was regarded

as a "poor" level of knowledge. The decision to use this cut-off score was based on the areas of knowledge considered to be "must know" by a group of experts on tobacco control in the country.

When assessing the overall exposure to activities promoting tobacco, responses to questions were allocated a weighted score, with a higher exposure status allocated a higher score. Applying a predetermined cut-off score of 7 to a range of scores from 0 to 15, the students were categorized as having a "high" or "low" level of exposure. The decision to use this cut-off score for responses was based on the consensus of a group of experts on tobacco control in the country.

The questions regarding how each adolescent responded to exposure to activities promoting tobacco or would respond to such activities in the future were analysed using a system of weighted scoring in which assertive responses were given a higher score. The maximum score possible was 14 and the minimum score was 0. Using a pre-agreed cut-off score of 7, the adolescents were categorized as having an "assertive" response (a score of 7 or more) or a "nonassertive" response (a score of less than 7).

Factors were cross-tabulated to the two levels of knowledge on tobacco-promotional activities and their associations were assessed using univariate analysis and multiple logistic regression analysis to determine factors adjusted for confounding effect. Sex, ethnicity, religion, level of education of both the mother and the father, engagement in extracurricular activities, type of school, status of smoking, and responses following exposure to tobacco-promotional activities were the factors assessed for their association with knowledge. A *P* value of 0.05 was used to determine significance.

RESULTS

The study included 498 adolescents, following a response rate of 99.6% (498/500). The mean age of the study participants was 14.9 years (standard deviation ± 0.37). The sample comprised a slightly higher proportion of females ($n = 280$, 56.2%). The majority (82.5%, $n = 411$) were Sinhalese and were living with their parents ($n = 457$, 91.8%). Most (68.9%, $n = 343$) participated in either sports or school clubs, or both. The percentage of current smokers was 3.2% ($n = 16$).

Knowledge of tobacco-promotional activities among adolescents

Adolescents were questioned regarding the current laws in the country relating to tobacco-promotional activities (see Table 1).

The majority of the adolescents (89.4%, $n = 445$) were aware that selling cigarettes to anyone below 21 years of age was against the law. The next most commonly known law was the prohibition of tobacco advertisements (52.4%, $n = 261$). The least-known law was prohibition of free distribution of tobacco products (0.6%, $n = 3$). It was noted that more than a quarter of the adolescents had responded "do not know" for six of the eight aspects related to law on which they were questioned.

Table 1: Distribution of the study population by their knowledge on laws to control tobacco-promotional activity in Sri Lanka

Law to control tobacco-promotional activity	Knowledge of law (total no. of adolescents = 498)		
	Yes n (%)	No n (%)	Do not know n (%)
Prohibition of selling tobacco products to persons under 21 years of age	445 (89.4)	24 (4.8)	29 (5.8)
Prohibition of installation of vending machines to dispense tobacco products	147 (29.5)	185 (37.1)	166 (33.4)
Prohibition of selling tobacco products without health warning and without indications of tar and nicotine content in each tobacco product	93 (18.7)	80 (16.1)	325 (65.3)
Prohibition of tobacco advertisements	261 (52.4)	106 (21.3)	131 (26.3)
Prohibition of sponsorships and similar by the tobacco trade	78 (15.8)	213 (42.8)	206 (41.4)
Prohibition of free distribution of tobacco products	3 (0.6)	250 (50.2)	245 (49.2)
Offences relating to trademarks of tobacco products	91 (18.3)	230 (46.2)	170 (34.1)
Offences relating to smoking in an area to which the public has access	231 (46.4)	182 (36.5)	85 (17.1)

The study population was also questioned about awareness of promotion strategies used by the tobacco trade (see Table 2). About half were aware that using social media (51.6%, $n = 257$), using incidents of smoking in electronic and printed media in a manner in which the habit is glamorized (53%, $n = 264$), and paying famous individuals to smoke in public (50%, $n = 249$) are used as tobacco-promotional activities. Approximately half (51.2%, $n = 255$) of the study population had “poor” knowledge of tobacco-promotional activities.

Exposure to tobacco-promotional activities among the adolescents

The adolescents were asked about their exposure to tobacco-promotional activities (see Table 3). A substantial proportion of study participants (41%, $n = 204$) were exposed to “a lot”

of media messages promoting tobacco smoking, on television, radio, billboards and posters, and in newspapers, magazines and movies, during a period of 30 days preceding the study. Three quarters of the study participants (74.3%, $n = 370$) had at least sometimes witnessed messages on tobacco promotion at sports events, fairs, concerts, community events or social gatherings, during the period of 30 days preceding the study, while approximately half of the students (47.64%, $n = 236$) had frequently seen actors smoking in television programmes, videos or movies. More than half of the study participants (63.3%, $n = 315$) claimed that they had not come across any cigarette brand names when they watched sports events or other programmes on the television during the period of 30 days preceding the study, while approximately half (46.6%, $n = 232$) had seen “a few” advertisements or promotions for cigarettes in newspapers or magazines during the period of 30 days preceding the study.

Table 2: Distribution of the study population by the awareness of promotion strategies used by the tobacco trade

Promotion strategy used by the tobacco trade	Awareness of promotion strategy (total no. of adolescents = 498)		
	Yes n (%)	No n (%)	Do not know n (%)
Using incidents of smoking in electronic and printed media in a manner in which the habit is glamorized	264 (53.0)	151 (30.3)	83 (16.7)
Posting promotive pictures/comments/messages in social media networks and other group-communication (chainsms/Facebook etc.) methods	257 (51.6)	171 (34.3)	70 (14.1)
Paying famous individuals to smoke in public	249 (50.0)	71 (14.3)	173 (37.5)
Free distribution among adolescents using peers/others	226 (45.4)	120 (24.1)	152 (30.5)
Using attractive males/females to smoke in public places	216 (43.4)	102 (20.5)	180 (36.1)
Using experts/ researchers to give misleading information	165 (31.1)	114 (22.9)	219 (44.0)
Increasing availability at social events that have higher participation of young people (e.g. musical shows)	170 (34.1)	106 (21.3)	222 (44.6)

Table 3: Distribution of the study population by exposure to media messages that promote tobacco smoking during the period of 30 days preceding the study

Media message promoting tobacco smoking	Frequency of exposure to media message (total no. of adolescents = 498)		
	A lot <i>n</i> (%)	Sometimes <i>n</i> (%)	Never <i>n</i> (%)
In television, radio, billboards, posters, newspapers, magazines or movies	204 (41.0)	161 (32.3)	133 (26.7)
At sports events, fairs, concerts, community events or social gatherings	133 (26.7)	237 (47.6)	128 (25.7)
Actors smoking in television, videos or movies	236 (47.6)	228 (45.8)	34 (6.8)
Cigarette brand names being displayed in sports events or other programmes on television	40 (8.0)	143 (28.7)	315 (63.3)
Advertisements or promotions for cigarettes being displayed in newspapers or magazines	53 (10.6)	232 (46.6)	213 (42.8)

When asked whether they owned something (T-shirt, pen, backpack, etc.) displaying a cigarette brand logo, only a minority (2.8%, $n = 14$) of adolescents reported owning such an item. When asked whether someone working for a cigarette company had offered them a free cigarette, the majority (99.6%, $n = 496$) said they had not had this experience. The majority (98.6%, $n = 491$) had never been offered a gift showing a tobacco logo. The majority (64.9%, $n = 323$) of the study participants had had a “low” level of exposure to tobacco-promotional activities.

Responses to tobacco-promotional activities among the adolescents

When adolescents were requested to indicate the way they in which they had reacted, or the likely way/ways in which they would respond, to being offered free cigarettes by someone working for a cigarette company, or to being offered gifts displaying a tobacco logo, the majority (63.1%, $n = 314$) said they had refused/would refuse the offer. More than half of the study participants (55.2%, $n = 275$) said that they had informed/would inform an adult about the incident. When asked whether they had carried out any activities in school against tobacco promotion, the majority of adolescents (77.1%, $n = 384$) said that they had not engaged in any activities against tobacco promotion in school. Those who responded positively to this question were asked about the activities they had carried out. The responses indicated that the activities included taking part in educational programmes (5.2%, $n = 6$), taking part in street dramas (2.6%, $n = 3$), and taking part in quizzes and essay and poster competitions (7.0%, $n = 8$) to build awareness against tobacco-promotional activities. The majority of adolescents (85.7%, $n = 427$) indicated that they would respond or had responded assertively to exposure to tobacco-promotional activities.

Factors associated with knowledge on tobacco-promotional activities among the adolescents

Univariate analysis was carried out to determine the relationship between knowledge of tobacco-promotional activities and characteristics of the study population (see Table 4).

Having a mother who had completed the General Certification of Education Ordinary Level (GCE O Level) examination or a higher-level examination (odds ratio [OR] 1.742, 95% confidence interval [CI] 1.127–2.692), a father who had completed the GCE O Level examination or a higher-level examination (OR 1.997, 95% CI 1.260–3.167), and attending a type 1AB school (OR 1.310, 95% CI 1.069–1.606) were significant factors associated with a good level of knowledge of tobacco-promotional activities, in the univariate analysis.

Results of the multiple logistic regression analysis revealed that the father’s highest level of education being GCE O Level or higher (adjusted OR 1.772, 95% CI 1.024–3.067) and the student attending a type 1AB school (adjusted OR 1.455, 95% CI 1.15–2.227) were the only factors associated with a good level of knowledge of tobacco-promotional activities when confounding effects of the variables were taken into consideration (see Table 4).

DISCUSSION

The FCTC bans advertising and promotional activities for tobacco. This strategy is designed to protect adolescents in particular from taking up smoking. Assessing knowledge of and exposure and responses to tobacco-promotional activities among adolescents in a rural setting provides an indication of the extent of implementation of the FCTC recommendations in a rural setting in Sri Lanka.

Table 4: Factors associated with “good” knowledge of tobacco-promotional activities, assessed by univariate and multivariate analyses

Characteristic (n)	Poor knowledge (total = 256)		Good knowledge (total = 242)		Univariate analysis		Multivariate analysis		
	n	%	n	%	OR	95% CI	OR	95% CI	P value
Sex									
Female (280)	147	57.4	133	55.0	1.128	0.785–1.623	1.445	0.95–2.227	0.85
Male (218)	109	42.6	109	45.0	Ref				
Mother’s highest education level achieved^a									
GCE O Level or higher qualification (287)	134	65.4	153	77.3	1.742	1.127–2.692	1.451	0.849–2.359	0.183
Below GCE O Level (116)	71	34.6	45	22.7	Ref				
Father’s highest education level achieved^b									
GCE O Level or higher qualification (312)	146	69.2	166	81.8	1.997	1.260–3.167	1.772	1.024–3.067	0.041
Below GCE O Level (102)	65	30.8	37	18.2	Ref				
Adolescent’s tobacco-use status									
Nonsmoker (482)	249	97.3	233	96.3	1.153	0.741–1.794	1.916	0.92–6.024	0.278
Current smoker (16)	7	2.7	9	3.7					
Category of the school attended by the adolescent									
1AB school (298)	140	54.7	158	63.5	1.310	1.069–1.606	1.455	1.150–2.227	0.48
1C school (200)	116	45.3	84	36.5	Ref				
Involvement in extracurricular activities									
Involved (343)	180	70.3	163	67.4	1.070	0.881–1.3	1.125	0.102–1.235	0.48
Not involved (155)	76	29.7	79	32.6	Ref				
A leader in clubs/groups in school									
Yes (148)	84	32.8	64	26.4	0.817	0.655–1.020	0.789	0.42–2.823	0.346
No (350)	172	67.2	178	73.6	Ref				
Responses to exposure to tobacco-promotional activities									
Assertive response (427)	215	84.0	212	87.6	1.092	0.824–1.44	0.739	0.379–1.373	0.338
Nonassertive response (71)	41	16.0	30	12.4	Ref				

CI: confidence interval; GCE O Level: General Certificate of Education Ordinary Level; OR: odds ratio; Ref: reference category.

^a Only the data of the 403 adolescents whose mothers were living were taken into account.

^b Only the data of the 414 adolescents whose mothers were living were taken into account.

The study revealed inadequate knowledge of the current laws in the country regarding tobacco-promotional activities and the stealth-marketing strategies used by the tobacco industry, with about only half (48.6%, $n = 242$) of the adolescents in the rural setting reporting a “good” level of knowledge of tobacco-promotional activities. One can argue that some of the laws on which they were questioned were too “advanced” to be

known by the adolescents. The results show some evidence of the validity of this argument, as more than one quarter of the adolescents responded “do not know” for six of the eight laws on which they were questioned.

A study conducted among college students with a mean age of 16.7 years in Guangzhou city in China also reported

inadequate knowledge related to the FCTC, with only 25.7% of nonsmokers and 30.7% of smokers knowing the laws.¹²

A cross-sectional study among university students, aimed at assessing awareness of existing legislation at the national level using a self-administered questionnaire, reported that knowledge of anti-smoking laws was low (11.3–25% of students).¹³ That study was carried out among 1104 students in universities in the Gaza Strip, Palestine, and the findings supported those of the present study.

A cross-sectional study among Jordanian women using a self-administered questionnaire revealed that only 52.2% were aware of workplace anti-smoking policies.¹⁴ The women were highly educated, with a college degree or higher level of education and a mean age of 34.6 years, and they were working in universities, unlike the participants of the present study who were adolescents.

The present study measured the level of exposure to tobacco-promotional activities, using a series of validated questions included in the GYTS. Though a majority (64.9%, $n = 323$) of the study participants had had a “low” level of overall exposure to tobacco-promotional activities, the present study revealed that many had been exposed to tobacco-promotional activities through media and had witnessed tobacco-promotional messages at events.

In the present study, only a few adolescents (2.8%, $n = 14$) reported owning an object displaying a cigarette brand logo. According to the data of the 2011 GYTS, 4.6% of adolescents in Sri Lanka owned an object displaying a cigarette company logo.¹⁰ The lower rate reported in the present study may be due to enforcement of NATA and the result of successful anti-tobacco campaigns.

According to the latest GYTS,¹⁰ 2.9% of students in Sri Lanka had been offered free cigarettes, while the corresponding percentage was 0.4% in the present study. Again, the lower rate reported in the present study can be attributed to successful implementation of the legislature and to successful anti-tobacco campaigns.

The present study showed that the majority of adolescents 85.7% ($n = 427$) had responded assertively or would respond assertively to tobacco-promotional activities; this is an encouraging finding.

The fact that the majority of adolescents (77.1%, $n = 384$) had not engaged in any activities against tobacco promotion in school indicates a lost opportunity to implement FCTC-recommended activities in schools.

Having a father with an education level of GCE O Level or higher was found to be associated with a good level of knowledge of tobacco-promotional activities in univariate (OR 1.997, CI 1.260–3.167) and multivariate (adjusted OR 1.772, 95% CI 1.024–3.067) analyses. A higher level of knowledge of tobacco-promotional activities among adolescents whose

parents had high levels of education was to be expected. This can be considered to be another benefit of improving school education among all age groups in the country.

Though exposure to tobacco-promotional activities was mostly low among the adolescents in rural areas, it is recommended that occurrences of exposure to advertising that is legally banned, but that had been experienced by the study population, be explored, and that the necessary legal action be taken to further reduce the exposure. A large proportion (87%) of adolescents in rural areas had given or would give an assertive response to exposure to tobacco-promotional activities. It is recommended that adolescents should be further empowered to give assertive responses, by teaching them effective actions.

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Access to free health-care services for the poor in tertiary hospitals of western Nepal: a descriptive study

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ABSTRACT

Background: Nepal is an underdeveloped country in which half of the total health expenditure is from out-of-pocket payments. Thus, the Government of Nepal introduced universal free health-care services up to the level of district hospitals, and targeted these services to poor and marginalized people in regional and subregional hospitals. The aim of this descriptive study was to explore the implementation and utilization of free health-care services by the target population (poor and marginalized people) in two tertiary-care hospitals in western Nepal, one with a social care unit (Western Regional Hospital) and one without a social care unit (Lumbini Zonal Hospital).

Methods: Medical records maintained by the two hospitals for one Nepali calendar year were collected and analysed, along with information from key informant interviews with staff from each hospital and patient exit interviews.

Results: Utilization of free health-care services by poor and marginalized people in the two tertiary-care hospitals was suboptimal: only 8.4% of patients using services were exempted from payment in Western Regional Hospital, whereas it was even fewer, at 2.7%, in Lumbini Zonal Hospital. There was also unintended use of services by nontarget people. Qualitative analysis indicated a lack of awareness of free health-care services among clients, and lack of awareness regarding target groups among staff at the hospitals. Importantly, many services were utilized by people from rural areas adjoining the district in which the hospital was situated.

Conclusion: Utilization of free health-care services by the target population in the two tertiary-care hospitals was very low. This was the result of poor dissemination of information about the free health-care programme by the hospitals to the target population, and also a lack of knowledge regarding free services and target groups among staff working in these hospitals. Thus, it is imperative to implement educational programmes for hospital staff and for poor and marginalized people. Unintended use of free services was also seen by nontarget groups; this suggests that there should further simplification of the process to identify target groups.

Key words: free health care, out-of-pocket expenditure, social service unit, target group, tertiary health care

BACKGROUND

The 1978 *Declaration of Alma-Ata*, expressing an urgent need for health for all by 2000, established that health is a fundamental human right and that the attainment of the highest possible level of health is a most important worldwide social goal, with action required from health-care sectors as well as social and economic sectors.¹ Despite this, there is evidence of a widening gap in access to basic health-care services in

resource-poor countries 30 years after the *Declaration of Alma-Ata*.² In low-income countries, most of the domestic health-care expenditure is out-of-pocket (OOP) payment, rather than prepaid insurance. In addition, the proportion of spending from public budgets is low.³ In low-income countries, direct OOP payments prevent many people from seeking care, resulting in catastrophic health spending.⁴ In Asia, households with higher income contribute more to health-care financing, and the more affluent families spend more in OOP expenses in low-income

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and middle-income Asian countries.⁵ In Nepal, the main source of health-care financing is OOP payment, which accounts for more than half of the total health expenditure in the country.^{5,6}

Universal health coverage aims to ensure that all people have access to the services they need without the risk of financial ruin.^{7,8} Establishment of universal health coverage requires systems that raise the bulk of funds through prepayment methods (for example, taxes and/or insurance), and then pool these funds to spread the financial risk of illness across the population.⁹ The state of health-care financing in Nepal is weak, as over 60% of the population lacks quality access to basic essential care such as maternity services.⁶ In addition to this, high reliance on OOP payments means that health care has a high catastrophic share of household spending, and this can lead to impoverishment or nonaccess by patients, as it is the most inequitable form of health-care financing.¹⁰

The mandate of *The Interim Constitution of Nepal 2063* (2007) emphasized that every citizen shall have the right to basic health-care services free of cost, as provided by law.¹¹ As a result, the Government of Nepal has provided essential health-care services free of charge in district hospitals, primary health-care centres, health posts and subhealth posts, to all people.¹² The free health-care policy covers consultation and treatment, minor surgery, obstetric emergencies, basic and comprehensive obstetric care, radiographs, laboratory services, essential drugs (for a week) and transport by ambulance to a higher-level facility when a patient is referred.¹³ As a result of this free health-care initiative, health-care access is steadily expanding; however, critical gaps still persist, and additional resources for health are required.⁶ Patients in tertiary-care health facilities are still required to pay for services.¹⁴

In order to increase the access to universal health-care services in tertiary-level hospitals for poor and marginalized people who have no ability to pay, the Ministry of Health and Population in Nepal has officially defined six target groups for free health-care services: poor (able to earn enough for adequate food for 6 months to fewer than 12 months in a year), ultrapoor (able to earn enough for adequate food for less than 6 months in a year), helpless/destitute, disabled, senior citizens aged 60 years or older, and female community health volunteers (FCHVs); these groups are entitled to free health-care services in tertiary-level hospitals.¹⁵

Some studies have evaluated the implementation of the free health-care policy in health posts and subhealth posts, and in hospitals up to district level; however, there is limited information available on the effectiveness of this policy for access to the health-care system, especially for the marginalized and poor.^{15–17} A study conducted in a regional hospital in the midwestern region of Nepal attempted to evaluate the situation regarding financial protection for patients and access to free services available at that facility.¹⁷ However, there is no such evidence available for the tertiary-level hospitals of the western region of Nepal. Therefore, the aim of this study was to assess the access to, and the state of, free health-care services for the target population in two tertiary-level hospitals in western Nepal.

METHODS

Selection of tertiary-level hospitals for data collection

Two tertiary-level public hospitals, Western Regional Hospital (WRH) located in Pokhara in Kaski district, and Lumbini Zonal Hospital (LZH) located in Butwal in Rupandehi district, were selected for this study, as being representative of referral hospitals in Nepal, based on their patient flow and number of referred patients from peripheral districts. The tertiary-level hospitals selected for this study are defined as referral hospitals that have specialized curative services, and patients are referred from community and district hospitals for specialized services. These two hospitals were chosen from the three public-funded tertiary hospitals in the western region of Nepal because of their very large patient flow and also because they have a budgetary allocation to provide free health care to the target population. The third public tertiary hospital in the region, Dhaulagiri Zonal Hospital, was not selected because it had been upgraded from a district hospital 1 year before the start of the study and was still in the early stages of generating referral-level service data at the time of this study.

The total number of available beds in WRH at the time of the study was 325 out of 500 sanctioned, owing to limited staff and hospital management. There was a high bed-occupancy rate of 71% and the hospital served mostly poor people from Kaski district and patients referred from surrounding district hospitals, such as those in Syangja, Manang, Tanahun, Gorkha and Lamjung. The total number of patients treated by WRH in the year of the study was 216 007. LZH, on the other hand, had 135 beds out of 200 sanctioned, with a high bed-occupancy rate of 82% and it mostly served poor people from Rupandehi district and patients referred from surrounding district hospitals, such as those in Gulmi, Arghakhanchi, Kapilvastu, Palpa and Nawalparasi, and those from peripheral facilities in the southern part of Syangja. The total number of hospital services provided by LZH in the study year was 177 817, which was less than the number provided by WRH.^{18,19} In addition to the public tertiary hospitals, there are two private teaching hospitals in Pokhara, Kaski district, with a total of 1125 beds. There is also one private teaching hospital and one medical college in Rupandehi district with 1020 beds altogether, and one private teaching hospital in Palpa district with 300 beds. Therefore, there are more tertiary hospitals in the vicinity of LZH than in the vicinity of WRH. Poor and marginalized people cannot afford to pay the service fees for private hospitals, and therefore they prefer to use public hospitals. However, those who can afford to pay the high fees prefer to attend private medical facilities.¹⁹

The Ministry of Health and Population (MoHP) in Nepal has been piloting the establishment of social service units (SSUs) in eight hospitals. The role of the SSU is to facilitate identification of target groups and enable free and partially free health-care service delivery to these populations.²⁰ The two hospitals selected for the present study differed in that an SSU was established in WRH in 2012, whereas there is no such unit in LZH.

Data collection method

One Nepali calendar year, 2069 (2011–2012), was chosen for information collection for this study. This year was selected based on the availability of records on free health-service provision for the target population in the chosen hospitals. There was no systematic record-keeping system for each individual patient on free health-care service provision prior to this year. Information on the patients who received free health-care services from the two selected hospitals was collected monthly, from Baishak (April) 2069 (2011) to Chaitra (March) 2069 (2012), for analysis.

Microsoft Excel software was used to produce a spreadsheet for data collection from the record registers of the two hospitals. The following information on each patient was collected for 1 year: name, age, sex, address (by district and village development committee (VDC), place of residence (urban or rural), target group (poor, ultrapoor, helpless/desitute, disabled, senior citizen or FCHV), marital status, ethnicity (as specified by the Health Management Information System: group 1, dalit; group 2, disadvantaged janajati; group 3, disadvantaged non-dalit; group 4, religious minority; group 5, relatively disadvantaged janajati; group 6, upper caste), types of health care received, and the name of the department where the patient accessed free health-care services. A data-collection team comprising four enumerators and a supervisor was formed at the Western Regional Health Directorate (WRHD), and this team visited both hospitals and collected patient information from the records.

Key informant and client interviews

A brief closed-ended interview questionnaire for the key informant interview was developed at WRHD and pretested at WRH. The questionnaire was revised based on pretest feedback, and a final version was produced. A total of six key informants, including a medical doctor, a matron, an official and a facilitator working in the SSU and a medical recorder, were interviewed at WRH, whereas a total of six key informants, including a medical doctor, a matron and paramedics, were interviewed at LZH. The following information was collected from the key informants: identification of target groups, facilitation processes within the hospital to access free health-care services by target groups, and problems faced by the hospital in delivery of free health-care services to target groups.

Similar to the key informant interviews, a brief close-ended interview checklist was developed, pretested and finalized for patient exit interviews. A total of 12 patients were interviewed, and information was collected on how they were able to reach the hospital, their satisfaction with the free services, how they obtained free health-care services, and what types of problems they had encountered to get the free health-care services.

The selection of participants was purposive, based on the amount of information that could be obtained from them. Face-to-face interviews were conducted by the supervisor in a quiet area within the hospital premises, where nobody could overhear the conversation.

Ethical issues

Ethical issues relating to this study, including data collection, analysis and interpretation, and the analysis report prepared by the research team, were approved by the research committee at WRHD. Informed consent for data collection and analysis was obtained from the medical superintendent of each hospital. Similarly, verbal consent was obtained before the interviews of key informants and exit patients. Confidentiality of the individuals and the information was maintained and the data provided were used only for the purposes of this study.

Data analysis

The secondary data collected from the hospital record registers were entered into the Excel spreadsheet. This was then imported to Statistical Package for Social Sciences (SPSS) software for quantitative analysis. Frequency tables required for analysis were then generated. The qualitative data collected through interview with key informants and patient exit surveys were analysed using Epi Info qualitative data analysis software, by counting the frequency of responses.

RESULTS

Free health-care services in Western Regional Hospital

Patient flow in WRH was relatively high. A total of 194 553 patients visited WRH for health care in the survey year (see Table 1). The average monthly flow of patients was 16 212, and the daily patient flow was 746 persons (assuming 261 working days for the hospital). Of the total number of patients, 16 417 (8.4%) received free health-care services, and hence the average flow of patients from the target groups was 1368 per month and 63 per day. The numbers of male (8116, 49.4%) and female (8301, 50.6%) patients were approximately equal. The geographical distribution showed that free health-care service utilization was highest in those from Kaski district (51.8%), where the hospital is located, while the remaining 48.2% of patients were from 57 peripheral districts. The poor (78.8%) and senior citizens (10.5%) were the two highest users of the service in the target groups. For the ethnic group analysis, patients from group 6, upper caste, utilized most free services (39.8%); those from group 1, which consists of the relatively poor dalit (lower caste) group, were the next highest users of free services (34.4%). The rural–urban distribution of patients using free services at WRH showed that most of the free services intended for the disadvantaged and poor were used by those living in rural areas (66.4%), and only 33.6% of free services were used by people living in urban areas.

The age group distribution, according to the hospital department in which the patients sought free services, showed that the highest number belonged to the age group 41–60 years in the general medicine department for free medicines (1961 patients), whereas the highest number belonged to the age group 21–40 years in the general medicine department for free investigations group (626 patients) (see Table 2).

Table 1: Sociodemographic characteristics of patients who received free health-care services at Western Regional Hospital

Characteristic	Patients accessing free services, <i>n</i> (%)	Male, <i>n</i> (%)	Female, <i>n</i> (%)
Total number of patients: 194 553	16 417 (8.4)	8116 (49.4)	8301 (50.6)
Rural–urban distribution			
Rural	10 911 (66.4)	5599 (51.3)	5312 (49.7)
Urban	5506 (33.6)	2702 (49.0)	2804 (51.0)
Geographical distribution			
Kaski district	8516 (51.8)	—	—
Other district	7901 (48.2)	—	—
Target group			
Poor	12 921 (78.8)	6725 (52.0)	6196 (48.0)
Ultrapoor	1003 (6.1)	437 (43.5)	566 (56.5)
Helpless	350 (2.1)	160 (45.7)	190 (54.3)
Senior citizen	1711 (10.5)	762 (44.5)	949 (55.5)
Female community health volunteer	31 (0.1)	2 (6.4)	29 (93.6)
Disabled	401 (2.4)	186 (46.3)	401 (53.7)
HMIS ethnic group			
Group 1: dalit	5655 (34.4)	2828 (50.0)	2827 (50.0)
Group 2: disadvantaged janajati	2150 (13.1)	1144 (53.2)	1006 (46.8)
Group 3: disadvantaged non-dalit	143 (0.9)	76 (53.1)	67 (46.9)
Group 4: religious minority	69 (0.4)	12 (17.4)	57 (82.6)
Group 5: relatively disadvantaged janajati	1864 (11.4)	954 (51.1)	910 (49.1)
Group 6: upper caste	6536 (39.8)	3249 (49.4)	3249 (50.6)

HMIS: Health Management Information System.

Source: compiled from the hospital record register available at Western Regional Hospital.

Free health-care services in Lumbini Zonal Hospital

The average patient flow per day was 500 in LZH. An average of 13 patients received free health-care services per clinic day. During the study period, a total of 3506 patients received free health-care services; this accounts for 2.7% of the total number of patients attending the hospital during the same period (130 398). The number of males using the free service was 1827 (52.1%). The geographical distribution of free health consultation in LZH showed that those from the home district (that is, Rupandehi district) accounted for 56.4%, and the remaining 43.6% were from 21 peripheral districts. The target group distribution of patients receiving free health care showed that most free service consultations were made by senior

citizens (82.4%), followed by the poor (12.3%). Similar to WRH, the free service users by ethnic group showed that most of the services were utilized by group 6, upper caste (52.5%), followed by group 1, the dalit (lower caste) group (19.4%). The urban–rural distribution of the free-service patients at LZH showed that most of the free services intended for the disadvantaged and poor community were used by those living in urban areas (64.4%) rather than those living in rural areas (35.6%) (see Table 3).

The age group distribution according to the hospital department in which the patients sought free service showed that the highest number of patients were those over 60 years, for both free medicines and free investigations. In addition, the general medicine department was most utilized for both free medicines

Table 2: Number of patients receiving free services according to age group and hospital department at Western Regional Hospital

Hospital department	Age (years), n (%)			
	Under 20	21–40	41–60	Over 60
Free medicines				
Medicine	794 (25.1)	1733 (54.0)	1961 (60.4)	1518 (63.3)
Surgery	352 (11.1)	402 (12.5)	547 (16.8)	363 (15.1)
Orthopaedics	414 (13.1)	514 (16.0)	332 (10.2)	89 (3.7)
Paediatrics	1184 (37.4)	99 (3.1)	46 (1.4)	54 (2.3)
Gynaecology	6 (0.2)	16 (0.5)	10 (0.3)	1 (<0.1)
Maternity	2 (0.1)	1 (<0.1))	11 (0.3)	0
Psychiatric	3 (0.1)	0	19 (0.6)	0
Skin and reproductive tract	12 (0.4)	7 (0.2)	21 (0.6)	1 (<0.1)
Other	396 (12.5)	437 (13.6)	300 (9.2)	371 (15.5)
Total	3163	3209	3247	2397
Free investigations				
Medicine	436 (47.9)	626 (42.5)	580 (47.6)	307 (45.9)
Surgery	64 (7.0)	134 (9.1)	119 (9.8)	83 (12.4)
Orthopaedics	59 (6.5)	76 (5.2)	128 (10.5)	91 (13.6)
Paediatrics	115 (12.6)	127 (8.6)	98 (8.0)	79 (11.8)
Gynaecology	25 (2.7)	37 (2.5)	21 (1.7)	9 (1.3)
Maternity	53 (5.82)	52 (3.5)	9 (0.7)	1 (0.1)
Psychiatric	4 (0.4)	16 (1.1)	15 (1.2)	6 (0.9)
Skin and reproductive tract	65 (7.1)	130 (8.8)	110 (9.0)	21 (3.1)
Other	90 (9.9)	274 (18.6)	138 (11.3)	72 (10.8)
Total	911	1472	1218	669

Source: compiled from the hospital record register available at Western Regional Hospital.

and free investigations. The number of free-service patients in the over-60 age group was 596 in the free medicine group, and 1381 for the same age group in the free investigation group (see Table 4).

Views of key informants on provision of free health-care services

Six health-care service providers from WRH and six from LZH were interviewed regarding their viewpoint on free health-care services. Knowledge of the six target groups was relatively lacking among the health-care providers and not one provider could identify all six target groups. All 12 health-care providers admitted that they provided free services and all

answered that the way to identify target groups was by asking patients their status; seven of 12 also said it was by looking at their outfit, while all six key informants at WRH said it was by looking at the referral slip from the SSU, and five of 12 said it was by looking at the recommendation letter from the VDC. Eight of 12 key informants linked the difficulty they faced in providing free services to the difficulty in identifying target groups. While all 12 key informants thought that the free health-care service was effective and 10 expressed their satisfaction in providing the free services, some still thought that there were some weaknesses in the system: eight thought it was due to poor awareness among all target groups regarding the availability of free services. This was highlighted again in their response to ways in which to improve free services: seven of 12 said the process of identifying target groups should be

Table 3: Sociodemographic characteristics of patients who received free health-care services at Lumbini Zonal Hospital

Characteristic	Patients accessing free services, n (%)	Male, n (%)	Female, n (%)
Total number of patients: 130 398	3506 (2.7)	1827 (52.1)	1679 (47.9)
Rural–urban distribution			
Rural	1247 (35.6)	681 (54.6)	566 (45.4)
Urban	2259 (64.4)	1146 (50.7)	1113 (49.3)
Geographical distribution			
Rupandehi district	1976 (56.4)	—	—
Other district	1529 (43.6)	—	—
Target group			
Poor	425 (12.3)	235 (54.8)	190 (45.2)
Ultrapoor	131 (3.8)	57 (43.5)	74 (56.5)
Helpless	44 (1.4)	18 (40.9)	26 (39.1)
Senior citizen	2884 (82.4)	1500 (52.0)	1384 (48.0)
Female community health volunteer	1 (<0.1)	0	1 (<0.1)
Disabled	2 (<0.1)	1 (<0.1)	1 (<0.1)
HMIS ethnic group			
Group 1: dalit	681 (19.4)	326 (47.8)	355 (52.2)
Group 2: disadvantaged janajati	491 (14.0)	247 (50.3)	244 (49.6)
Group 3: disadvantaged non-dalit	184 (5.2)	81 (44.0)	103 (56.0)
Group 4: religious minority	56 (1.6)	34 (60.7)	22 (39.3)
Group 5: relatively disadvantaged janajati	255 (7.3)	146 (57.2)	109 (42.8)
Group 6: upper caste	1839 (52.5)	993 (54.0)	846 (46.0)

HMIS: Health Management Information System.

Source: compiled from the hospital record register available at Lumbini Zonal Hospital.

made more effective and easy. Similarly, six informants also said that there should be easy availability of free medicines, services and positioning of appropriate human resources (quantity and quality).

Patients' satisfaction with free health-care services

Twelve patients, six from WRH and six from LZH, among those who came to use the free health-care services were selected for the patient exit survey. There were mixed views regarding the ease of availability of free services: six of the 12 thought the services were readily available and the remaining half thought that they were not readily available. The fact that there were seven patients who received information about

free services from the health-care providers after attending the hospital indicated that there was not adequate knowledge regarding free services among the target population, and this was preventing them from actively seeking these services. While eight patients in the survey were satisfied with the free services, and seven did not feel that they had any difficulty while utilizing the services, all 12 expressed that there was a need to increase awareness regarding the free services among the target groups.

Performance of SSUs

As stated in Social Service Unit Establishment and Operational Guidelines, 2069 (2012)²⁰ of MoHP, a separate office space is allocated for the SSU in WRH, with same hours of operation

Table 4: Number of patients receiving free services according to age group and hospital department at Lumbini Zonal Hospital

Hospital department	Age (years), n (%)			
	Under 20	21–40	41–60	Over 60
Free medicines				
Medicine	19 (45.2)	49 (4.0)	27 (37.5)	596 (54.0)
Surgery	2 (4.8)	4 (3.2)	0	66 (6.0)
Orthopaedics	2 (4.8)	11 (8.9)	10 (13.9)	165 (14.9)
Paediatrics	7 (16.7)	0	0	2 (0.2)
Gynaecology	0	11 (8.9)	1 (1.3)	12 (1.09)
Maternity	0	2 (1.6)	4 (5.5)	2 (0.2)
Psychiatric	1 (2.4)	2 (1.6)	1 (1.3)	6 (0.5)
Skin and reproductive tract	4 (9.5)	19 (15.4)	9 (12.5)	80 (7.2)
Other	7 (16.7)	25 (20.3)	20 (27.8)	175 (15.8)
Total	42	123	72	1104
Free investigations				
Medicine	24 (42.9)	105 (71.4)	59 (67.0)	1381 (72.4)
Surgery	6 (10.7)	8 (5.4)	4 (4.5)	105 (5.5)
Orthopaedics	2 (3.6)	7 (4.8)	10 (11.4)	162 (8.5)
Paediatrics	9 (16.1)	0	0	2 (0.1)
Gynaecology	0	4 (2.7)	1 (1.1)	13 (0.7)
Maternity	0	1 (0.7)	0	2 (0.1)
Skin and reproductive tract	2 (3.6)	4 (2.7)	2 (2.3)	55 (2.9)
Other	13 (23.2)	18 (12.2)	12 (13.6)	187 (9.8)
Total	56	147	88	1907

Source: compiled from the hospital record register available at Lumbini Zonal Hospital.

as the hospital. Patients who know of the SSU go straight to the front desk at the SSU. Those who fall into the target groups but do not know about the SSU go first to the outpatient department (OPD) and are taken to the SSU by support staff of the respective OPD section. SSU unit staff then identify patients belonging to the target groups and provide them with a slip for free treatment. The clients then go to the appropriate OPD or inpatient department, as directed by SSU staff, with the treatment slip for a check-up and treatment. The SSU in WRH has two administrative staff: one unit chief and one facilitator working from 10:00 to 17:00. This unit is equipped with a computer and information is recorded on software generated for SSUs by the government. The identification of target groups was based on criteria as outlined by the SSU guidelines. The SSU in WRH has been operating according to *Social Service Unit establishment and operational guidelines 2069 (2012)*.²⁰ All those who came to the hospital and who met

the criteria for inclusion in the target groups were provided with free services. However, the patient exit survey indicated that six patients, three of whom attended WRH, did not feel that the free services were readily available. Also, the patient exit survey showed that SSU staff members were not readily available to facilitate free services for the target population; therefore, it is essential that SSU staff are available at all times.

Unlike WRH, there is no SSU at LZH. Patients entitled to free care were identified by those who were involved in patient care and treatment, and the identification was usually based on the second criterion mentioned in the *Social Service Unit establishment and operational guidelines 2069 (2012)* (that is, by looking at the appearance and outfit of the patient).²⁰ In some instances, poor people brought an identification document from their VDC, which was also sometimes used at LZH. One particular patient, when interviewed in the exit survey,

expressed his disappointment that he was not provided with free services though he presented an identification document from his VDC showing that he was poor. One disadvantage that was clearly identified to be the result of the lack of an SSU at LZH was that it created difficulty and inequality in identification of target groups. Also, the data of patients accessing free health care, and information on expenditure, was not properly maintained in the absence of an SSU.

It should be noted that, although there was no SSU at LZH, both hospitals received aid from the government for the expenses of free health-care services.

DISCUSSION

The results of this study show that the percentage of patients exempted from payment was 8.4% in WRH and 2.7% in LZH. A similar study by Basnet et al. in 2013 in a regional hospital in the midwestern region of Nepal showed that 10.8% of patients were exempted from payment.¹⁷ The percentage of patients receiving free services was very low at LZH and moderately low at WRH, although the population census report of 2011 showed the population of Rupandehi district to be much larger (880 196) than that of Kaski (492 098).¹⁹ The poor educational programme provided by the hospitals to inform the target groups on the availability of free health-care services contributed to the low number of patients receiving free services at LZH.

This study found that the free services were utilized mostly by poor patients (78.8%) and senior citizens (10.5%) at WRH, Pokhara. The scenario was different at LZH, Butwal; the free services were utilized mostly by senior citizens (82.4%), followed by poor patients (12.3%), and this clearly shows that more poor patients were missed at LZH than at WRH. A survey done in 13 districts by RTI International and CARE Nepal in December 2009, to assess implementation of the free health-care policy, found that use of free services in primary health-care centres and district hospitals was more common in ultrapoor groups, followed by poor groups in all hospital departments: emergency, outpatient and inpatient.¹⁴ The reason for the difference in utilization of free services by different groups between our study and that of RTI International was that it was difficult for our research team to determine which group the clients belonged to, either ultrapoor or poor, based on the records maintained at the two hospitals.

People in the target groups were identified either by presentation of an identification card, or by the staff involved in treatment analysing the appearance of patients. At WRH, the card was the most common method for identification, although the staff assessment method was used in the absence of an identification card. At LZH, the staff assessment was the most common means of identifying patients in target groups, because this hospital lacked an SSU. Nevertheless, this policy does not distinguish between the poor and ultrapoor, and the government should produce a simple, clear and practical definition of target groups.²¹ A similar study by Basnet et al. in 2013 in a regional hospital of Surkhet district also did not differentiate between the poor and ultrapoor; that study showed that the poor used free health care in the highest numbers (71.9%).¹⁷

The present study showed that most of the groups using the free services were upper-caste patients and poor patients, and also some nontarget groups. Similar to the present study, there are reports showing an increasing demand for free services because of unnecessary use of health care by nontarget groups, thus leading to a fall in the quality of the services and increasing health-care costs.^{21,22} The upper-caste poor clients who utilized most of the free services in the present study had a good awareness of the access to free services, but the target groups from other marginalized caste groups, for whom the service is intended, had relatively poor knowledge of the free services; other studies have reported similar findings.²¹ One of the aims of the free service is to increase utilization of services by women; however, the present study showed almost equal numbers of males and females accessing services. The percentage of females using the free services was 50.6% at WRH and 47.9% at LZH.

The study by Basnet et al. showed that 83.3% of patients using free services were from the geographical district where the hospital was situated,¹⁷ while the percentages in the present study were 51.8% for WRH and 56.4% for LZH. This shows that access to these hospitals is comparatively easier than access to the regional hospital in Surkhet for people from outside the geographical districts of WRH and LZH. One of the important factors indicating ease of access to a hospital is the number of people from rural areas utilizing the free services; in the present study WRH had a high percentage of referrals from rural areas at 66.4%, while it was 35.6% at LZH.

Our research suffers from limitations such as insufficient sample size for qualitative research. Therefore, it gives preliminary findings only, and further research, including more interviews with staff and patients, is required to improve the current utilization of free health-care services in tertiary-level hospitals by the target groups. This will help to identify the reasons for unintended use of free services, as well as to explore the reasons why poor and vulnerable people are not utilizing the free services to which they are entitled.

Conclusion

An important conclusion of this work is that there was very low access to and utilization of free health-care services in the two tertiary-care hospitals in western Nepal. This was mainly because the hospitals did not provide an adequate educational programme to inform the population about the availability of free health-care services, and also a lack of knowledge regarding free services and target groups among staff working in the hospitals. There was also unintended use of free health-care services by nontarget groups, and this indicates the need for further simplification of the criteria used for identifying target groups. Based on the findings of this study, it is recommended that: (i) there are educational programmes for hospital staff to increase their awareness of the free health-care services, and inform them how to correctly identify target groups or how to help provide the free services to which target groups are entitled; (ii) hospitals initiate awareness/educational programmes to provide information about free health-care services to poor and marginalized caste groups; (iii) there are proper recording

and reporting systems in place for the free health-care services, especially at LZH; (iv) an SSU is established at LZH to help poor and marginalized patients access the services; (v) the process of identifying target groups is simplified, as this could help to make free health-care services more easily available; and (vi) target groups have easy availability and accessibility of medicines and other services.

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HIV prevalence in blood donors and recipients in Pakistan: a meta-analysis and analysis of blood-bank data

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ABSTRACT

Background: The first instances of HIV-antibody detection in donated blood in Pakistan were reported in 1988. Since then, documentation of HIV in blood donors and of rates of transmission via transfusion has been limited. Previously assumed to have a low prevalence, HIV is an increasing health concern in Pakistan. Since there is no national, centralized blood-banking system, there are no reliable data on which to base estimated risks of transfusion-associated HIV infection. This study was therefore conducted to estimate the prevalence of HIV in blood donors and recipients in Pakistan between 1988 and 2012.

Methods: Meta-analyses were undertaken of reported prevalences of HIV in blood donors and recipients published during 1988–2012. Papers were identified by searching PubMed, Google, CINAHL and PakMediNet and the websites of the World Health Organization, the national HIV/AIDS Surveillance Project and the National AIDS Control Programme of Pakistan. In addition, the 1998–2012 records of the Aga Khan University blood bank were analysed.

Results: The 254 abstracts identified at the preliminary search were reviewed and, after removal of duplications, case-reports, editorials and reviews, 32 papers were selected that met the inclusion criteria. All studies that reported on HIV antibodies in blood donors/recipients were included, irrespective of the methodology used. Since seroconversion had only been confirmed through supplemental testing in a few papers, the results were analysed separately for reports based on screening only and confirmed cases. A total of 142 of 2 023 379 blood donors and 4 of 3632 blood recipients were HIV positive, giving an overall pooled seroprevalence of 0.00111% in blood donors and 0.00325% in blood recipients. The annual prevalences of HIV in donors at the Aga Khan University blood banks were similar, ranging from 0.013% to 0.116%.

Conclusion: Very few reports on HIV in blood donors in Pakistan could be retrieved, and the overall pooled prevalence is low. However, the limited data and confounding factors mean that these results may significantly underestimate the true situation. It is recommended that a complete survey of blood banks should be conducted throughout the country, in order to provide a more reliable estimate of the risk of transfusion-associated HIV infection in Pakistan.

Key words: blood bank, blood donors, blood transfusion, HIV, Pakistan, transfusion-transmitted infection

BACKGROUND

Situated in South Asia, Pakistan is home to 180 million people, with a 54.7% literacy rate and 61.7% of its people residing in rural towns.¹ Though there are 1830 blood providers in the

public and private sectors and nongovernmental organizations (NGOs),² the total number of units of blood collected in the entire country is not known exactly. According to an update in 2009 from the Pakistan Society of Haematology, approximately 3 million units are collected in various thalassaemia centres.³

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In 2000, Luby et al. estimated that blood collection in Karachi is done primarily on a transfusion-exchange (75%) or a paid basis (25%).⁴ Some of the challenges to the transfusion services include lack of a national blood policy, inadequate recruitment and donor selection,⁵ and the cost of screening kits, coupled with periodic lack of availability of reagents.^{6,7}

The Government of Pakistan has taken several initiatives to reform blood-safety systems in the country. In 1986–1987, the National AIDS Control Programme (NACP) was initiated, with a focus on HIV diagnosis in hospitalized patients suspected of being infected with HIV, but later shifted its scope towards HIV prevention, which included mitigation against transfusion-transmitted HIV. NACP was financed by the World Health Organization (WHO) and other donors initially, until the formation of the Joint United Nations Programme on HIV/AIDS (UNAIDS) in 1996.⁸ An important step was promulgation of the Safe Blood Transfusion Act by provincial legislature in 1997, under which the Sindh Blood Transfusion Authority (SBTA) was formed.⁹ SBTA enrolled 146 banks in the province of Sindh that met its standards, and closed down 126 substandard blood banks.¹⁰ Similar initiatives were subsequently taken by other provinces. More recently, the government officially consolidated its blood-safety initiatives, by establishing a National Blood Transfusion Project (NBTP) in March 2009. With NBTB established at the national and provincial levels, the foundation has now been laid for a system that will ensure adequate and nationwide access to a safe, adequate and affordable blood supply.¹¹ The German Federal Ministry for Economic Cooperation and Development is providing technical and financial support for this initiative.

In a recent meta-analysis, the national prevalence of hepatitis C and B virus in blood donors in Pakistan was estimated to be 2.8% and 2.3% respectively.¹² However, there is a paucity of data on the prevalence of HIV in blood donors and rates of transfusion-transmitted HIV. For example, it is not known whether the seroprevalence of HIV is static or increasing in Pakistani blood donors. Initial reports of transfusion-associated HIV were published in 1988 by Mujeeb and Hashmi¹³ and Khanani et al.¹⁴ For 2013, the estimated adult prevalence of HIV in Pakistan was 0.07% and there were an estimated 2200 HIV-related deaths.¹ In 2009, UNAIDS Pakistan and NACP estimated that there were 98 000 (range 79 000–120 000) HIV cases in Pakistan, with an overall HIV prevalence of less than 0.05%; and that seroprevalence among injecting drug users (an estimated prevalence of 20%) and their sexual contacts, including male and transgender *hijra* sex workers, was increasing.⁸

Since documentation of transfusion transmission of HIV has been limited, this study aimed to estimate the prevalence of HIV in blood donors and recipients during 1988–2012, through meta-analysis of published data. In addition, data from the Aga Khan University blood bank records for 1998–2012 were analysed.

METHODS

Search strategy

The MOOSE (Meta-analysis Of Observational Studies in Epidemiology) group checklist for reporting meta-analysis of observational studies was used.¹⁵ Two authors conducted individual searches for papers published in the past 25 years (from January 1988 to December 2012), using all databases available to the institute, i.e. PubMed, Google search, CINAHL and PakMediNet. The latter is a search engine that encompasses the non-indexed locally published literature. The following key words were used: “HIV” AND “blood donors”, “blood recipients”, “multiply transfused”, “thalassaemia”, “haemophilia” AND “Pakistan”. Additional articles were identified by searching for specific authors in this field and through the cited references of relevant articles from the Google search engine. WHO, the Pakistan HIV/AIDS Surveillance Project and NACP were also searched, to capture any additional relevant papers. Bibliographies of published full manuscripts were searched for additional manuscripts. Only papers published in English were included, as local medical journals are published in this language.

Inclusion and exclusion criteria

The preliminary search yielded 254 abstracts, 190 from PubMed, 21 from CINAHL and 43 from PakMediNet. After removing duplications, two experts independently selected 38 abstracts that were relevant. Case-reports, editorials and reviews ($n = 6$) were excluded from further analysis; 32 papers met the inclusion criteria for review. All studies that reported on HIV antibodies in blood donors/recipients were included, irrespective of the methodology used. Since only a few papers reported that seroconversion had been confirmed through supplemental testing, the results were analysed separately for reports based on screening only and confirmed cases.

Data handling and statistical analysis

Data regarding the time period of the study, region (province), population of study (donor or recipient), total sample size, percentages and numbers of positive cases, and methodology were extracted from the articles. If the same study included both donors and recipients or had been done in more than one location, it was split and the results were indicated separately according to the group. Where results were mentioned in percentages, the absolute values were calculated from the population denominator. STATA 12 was used to analyse the data for the pooled prevalence. All meta-analyses were evaluated for heterogeneity, using the χ^2 -based I^2 test. I^2 values were interpreted as: 0%, 25%, 50% and 75%, to indicate no heterogeneity, low-level, moderate-level or high-level heterogeneity, respectively. For moderate-level or high-level heterogeneity, a random-effects meta-analysis was performed. Forest plots for unadjusted prevalence estimates with 95% confidence limits were generated.¹⁶ A P value of <0.05 was considered significant.

Aga Khan University blood bank data, 1998–2012

Blood-bank donor data from the records of the Aga Khan University were also analysed. Data from all blood donors enrolled and tested for HIV between 1998 and 2012 were included. The methodology was enzyme-linked immunosorbent assay (ELISA; AxSYM and ARCHITECT ci1000, Abbott Diagnostic Division, Abbott Park, IL, United States of America) until 2009 and chemiluminescence (Vitros[®], Ortho Clinical Diagnostics, Johnson & Johnson, Raritan, NY, United States of America) in later years. From July 2011, reactive samples were retested on another instrument (Cobas[®] 601e analyser, Roche Diagnostics GmbH, Mannheim, Germany). Repeatedly reactive samples were further confirmed through western blot.

RESULTS

The full texts of 32 published papers were eligible for analysis. Twenty-five manuscripts related to HIV prevalence in blood donors were found,^{17–41} six that described HIV risk in both donors and recipients,^{13,14,42–45} and only one study that was dedicated exclusively to HIV seroprevalence in transfusion recipients.⁴⁶

HIV seroprevalence and methodology used in blood donors

Thirty-one studies were evaluated to describe the prevalence of HIV in blood donors in Pakistan.^{13,14,17–45} The overall pooled seroprevalence of HIV in blood donors was 0.00111% (95% confidence interval [CI] = -0.00044% to 0.00267%), $I^2 = 89.7%$, $P < 0.00001$ (see Fig. 1). The data were from nine large cities of the country and 10 studies were conducted in the city of Karachi alone,^{13,14,17–20,38,40, 42,45} while six and four were conducted in Lahore^{25,28,30,36,37,44} and Peshawar,^{22,39,41,43} respectively. ELISA was the predominant screening technology used in 27 studies,^{13,14,17–20,22,23,25,29,32–41,42,45} one paper did not describe the methodology used,³¹ while the remaining three studies were based exclusively either on immunochromatographic testing^{24,30} or latex agglutination.²¹ During 1988–2012, a total of 142 donors were reported to have HIV antibodies. Of these, 128 of 652 019 (0.02%) tests were based on ELISA, while in four reports, 14 of 1 350 205 (0.001%) tests were confirmed with supplemental testing.^{14,18,25,40} There was no HIV recorded in 18 of the studies.^{13,17,19–21,24,27,29–32,34,38,41,42–45} A total of 11 public-sector blood banks associated with various teaching hospitals yielded 27 reports, with a total of 1 875 532 tested donors identifying 125 subjects (0.0067%) with HIV antibodies. In contrast, only three studies were conducted at two private hospital blood banks linked to academic institutes.^{18,40,45} They reported HIV in two of 89 101 blood donors (0.002%) who were screened. Four papers described HIV seroconversion in 14 of the 52 625 blood donors (0.03%) enrolled in four NGOs,^{24,35,36,41} while one report was the combined effort of an NGO with a teaching hospital.²⁷ One study did not mention the names of the blood banks that

took part in the study;¹⁴ this was a small study with 121 donors, reporting HIV in one donor.

Donor sex and HIV

A total of 17 of the 31 studies on blood donors did not report the sex of the participants. Fourteen reports described 285 208 sex-wise donations, including 258 628 male (90.7%) and 26 580 female (9.3%) donors.^{18–21,23,27,28,30–32,37,38,42,45} However, except for one study,¹⁸ the HIV results were not delineated with respect to sex.

Donor type and HIV

Donor types were described in 15 reports only. Khanani et al. ($n = 121$) reported the results exclusively in 121 paid/professional donors and found a single (0.8%) HIV-reactive donation.¹⁴ Similarly, Mujeeb and Mehmood described the HIV risk in 839 family/replacement or exchange-transfusion donors and the incidence was reported as nil.¹⁹ Six reports described the HIV risk solely in unpaid voluntary donors,^{20,27,28,30,36,44} and the result was reported as zero in four reports,^{20,27,30,44} and 0.2% and 0.045% in two other studies.^{28,36} However, the latter studies were ELISA based and their results were not confirmed through supplemental testing. Four papers described the HIV seroprevalence in combined unpaid voluntary or family/replacement donors,^{23,26,33,37} and the HIV reactivity ranged from 0.004% to 0.23%. The HIV prevalence in paid and unpaid donors from slum areas of Karachi was reported in three reports,^{13,17,42} but it was reported as nil.

Trend of HIV in blood donors

The data did not show any rising or declining trend of HIV over a period of 25 years from 1988 when initial cases of HIV in blood donations were reported.^{13,14} A frequency of <0.3% was maintained through the study period, from various places of the country, irrespective of the donor type and the category of blood bank.

HIV seroprevalence in blood donors at Aga Khan University blood bank

From 1998 to 2012, 306 316 blood donors were enrolled and tested for HIV at the Aga Khan University blood bank; of these, 95.5% were male and 87% were family/replacement donors. Table 1 summarizes the overall, donor-type and sex-wise details for HIV seroprevalence. There were 167 donors who tested positive for HIV. Results of western blot on a total of 16 samples were as follows: positive ($n = 5$ or 31%), indeterminate ($n = 6$ or 38%) and negative ($n = 5$ or 31%). Donors with indeterminate results were not followed up. Also, overall, in male and family/exchange donors, the seroprevalence of HIV was low, ranging from 0.013% to 0.116%. Seroprevalence was not computed for female and voluntary donors because of small denominators.

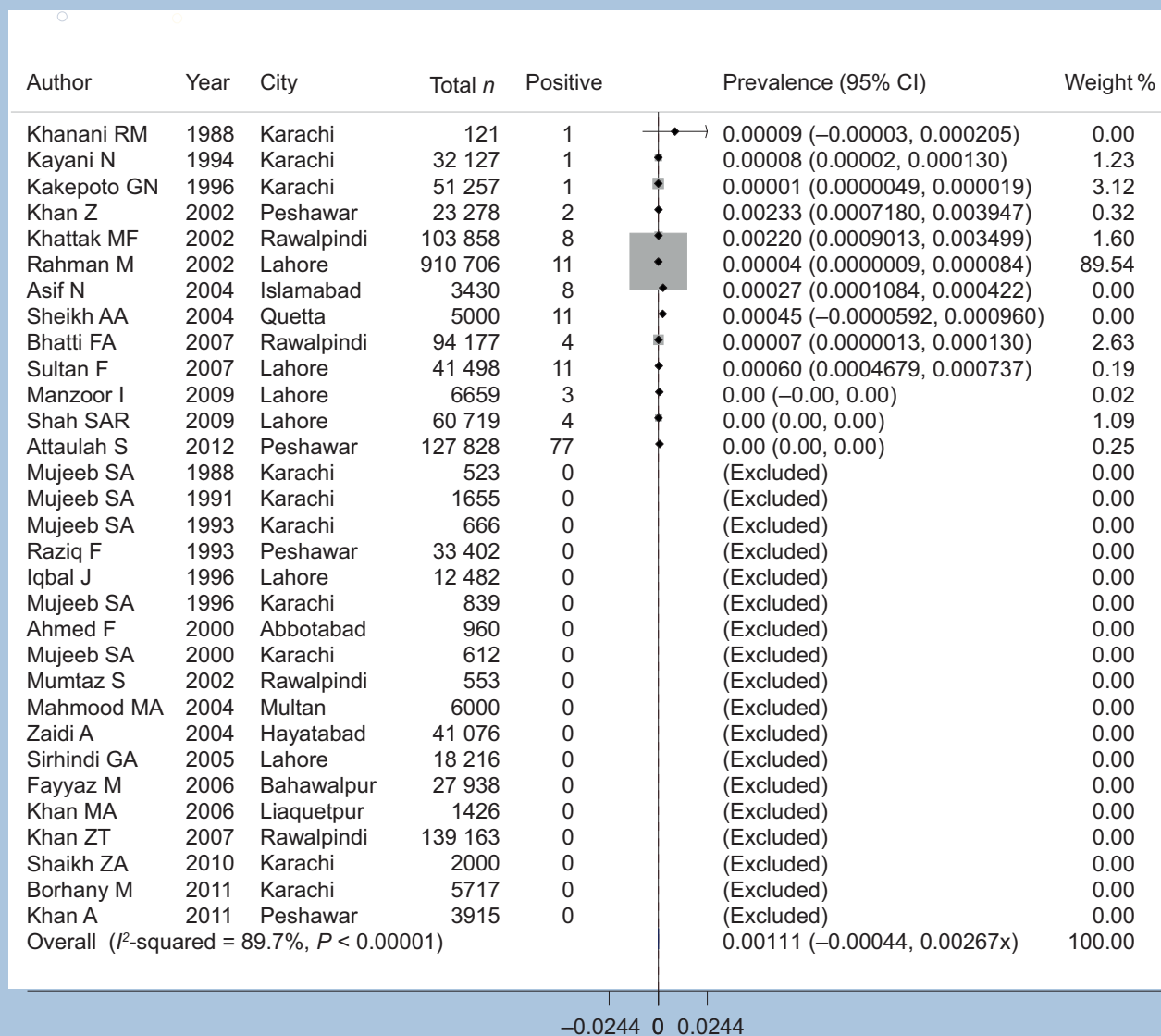


Figure 1: Prevalence of HIV positivity in blood donors in Pakistan

Forest plot showing prevalence (%) estimates (black solid diamonds) with 95% confidence intervals (bars). Shaded boxes denote the weight allocated to each study based on sample size. The overall pooled prevalence estimate 0.00111% (95% confidence interval [CI] = -0.00044% to 0.00267%) was too low to be plotted on the graph.

HIV in transfusion recipients

Seven studies described the prevalence of HIV in multiply transfused blood recipients, including those with haemophilia,^{14,45} and polytransfused^{13,14,42-44,46} and haemodialysed^{42,44} patients. Except for one study,⁴⁵ HIV results were confirmed through supplemental testing (western blot or p24 antigen). The pooled data indicated that only 3632 transfusion recipients were

studied and only four were reactive for HIV, with an overall prevalence of 0.00325% (95% CI = -0.00135 to 0.00648; see Fig. 2). However, there are too few data to draw any meaningful conclusions regarding the prevalence of HIV in blood recipients. All HIV-reactive patients had received multiple transfusions; 888 of them had had transfusions with unscreened blood products,¹³ and two were reported to have acquired HIV through blood transfusions.¹³

Table 1. HIV seroprevalence in blood donors at Aga Khan University blood bank

Year	Donors, <i>n</i>	Males, <i>n</i> (%)	Family/ replacement donors, <i>n</i> (%)	% HIV prevalence (95% CI) in donors	% HIV prevalence (95% CI) in male donors	% HIV prevalence in family/replacement donors
1998	15 070	14 317 (95)	11 235 (75)	0.013 (0.011 to 0.015)	0.014 (0.012 to 0.014)	0.018 (0.015 to 0.020)
1999	12 300	11 685 (95)	8 636 (70)	0.024 (0.022 to 0.027)	0.026 (0.023 to 0.026)	0.035 (0.031 to 0.039)
2000	15 194	14 434 (95)	11 700 (77)	0.007 (0.005 to 0.008)	0.007 (0.006 to 0.007)	0.009 (0.007 to 0.010)
2001	14 992	14 242 (95)	11 669 (78)	0.013 (0.012 to 0.015)	0.014 (0.012 to 0.014)	0.017 (0.015 to 0.019)
2002	16 333	15 516 (95)	13 180 (81)	0.012 (0.011 to 0.014)	0.013 (0.011 to 0.013)	0.015 (0.013 to 0.017)
2003	18 384	17 465 (95)	15 402 (84)	0.065 (0.062 to 0.069)	0.069 (0.063 to 0.067)	0.065 (0.061 to 0.069)
2004	21 849	20 757 (95)	19 037 (87)	0.064 (0.061 to 0.067)	0.063 (0.062 to 0.066)	0.074 (0.070 to 0.077)
2005	21 411	19 929 (93)	18 368 (86)	0.051 (0.048 to 0.054)	0.055 (0.050 to 0.053)	0.038 (0.035 to 0.041)
2006	22 924	21 632 (94)	20 616 (90)	0.074 (0.071 to 0.078)	0.074 (0.073 to 0.076)	0.058 (0.055 to 0.061)
2007	24 994	24 082 (96)	23 073 (92)	0.120 (0.116 to 0.124)	0.116 (0.112 to 0.120)	0.104 (0.100 to 0.108)
2008	24 191	23 128 (96)	21 434 (87)	0.037 (0.035 to 0.040)	0.039 (0.036 to 0.038)	0.033 (0.030 to 0.035)
2009	25 427	24 709 (97)	24 115 (95)	0.071 (0.068 to 0.074)	0.073 (0.069 to 0.072)	0.070 (0.067 to 0.074)
2010	25 116	24 335 (97)	23 496 (94)	0.044 (0.041 to 0.046)	0.045 (0.043 to 0.045)	0.047 (0.044 to 0.050)
2011	24 572	23 864 (97)	23 120 (94)	0.094 (0.089 to 0.097)	0.096 (0.092 to 0.095)	0.095 (0.091 to 0.099)
2012	23 559	22 557 (96)	21 615 (92)	0.051 (0.048 to 0.054)	0.049 (0.046 to 0.052)	0.051 (0.048 to 0.054)

CI: confidence interval.

DISCUSSION

This study showed that the seroprevalence of HIV in blood donors in Pakistan is low at 0.0011%. Although repeatedly transfused patients demonstrated an overall HIV seroprevalence of 0.003%, the number of patients studied was too small to draw any conclusion. With a national prevalence rate of 2–3% for viral hepatitis B and C in blood donors,¹² HIV appears to be lowest among the various transfusion-transmitted viral infections. This seems to be even lower than HIV seroprevalence in blood donors reported from neighbouring countries, which is 0.249% for India,⁴⁷ 0.004% for the Islamic Republic of Iran,⁴⁸ and 0.1% for Nepal.⁴⁹ Overall, the prevalence seems low, but the limited number of studies retrieved from the published literature may mean that the calculated figure does not represent the true prevalence.

The literature search revealed that reports for HIV prevalence in blood donors were available from only 11 public-sector, 4 NGO and 2 private blood banks. This indicates that published reports are not representative of all operational blood banks in the country. In addition, it cannot be assumed that testing is done routinely, since HIV kits are periodically missing in public-sector blood banks.⁷ Since there is no centralized blood banking at national level, it is hard to analyse the situation with confidence. Studies have highlighted the alarming situation in blood banks, whereby prospective donors may be neither screened nor interviewed regarding high-risk behaviour.^{4,9}

There is currently no insight into the type of blood donation and HIV surveillance in private blood banks and the majority of public blood banks, 20–25% of which are dependent on paid professional donors. These are potentially injection drug users, among whom the reported HIV prevalence is about 20%.⁵⁰ One can assume that the reports of low HIV prevalence are far from reality. Other issues observed were the variance in methodology, lack of supplemental testing and small sample size. The poor HIV surveillance and lack of record keeping in banks would not allow for tracking of blood donors. This would result in the same HIV-positive subject donating blood at several places. Individuals reported as replacement donors might include paid donors as well.²⁵

In 2000, Luby et al. surveyed 37 randomly selected facilities from a total of 87 in Karachi.⁴ Only 24 agreed to participate. Twelve (50%) of the facilities reported regularly utilizing paid blood donors, while only six (25%) actively recruited volunteer donors. Only 8% of the surveyed facilities ask donors about intravascular drug abuse, and none was prepared to ask about high-risk sexual behaviour. Only 55% were screening for HIV. It is worth noting that HIV is a taboo subject in the social and religious culture of the country and therefore direct questioning related to HIV is often avoided in the blood banks.

In 2005, 63 blood bank services were visited by field workers under supervision of NACP. A report was prepared by third-party evaluation of the quality of HIV screening of blood products.² The report warned that 40% of observed blood banks

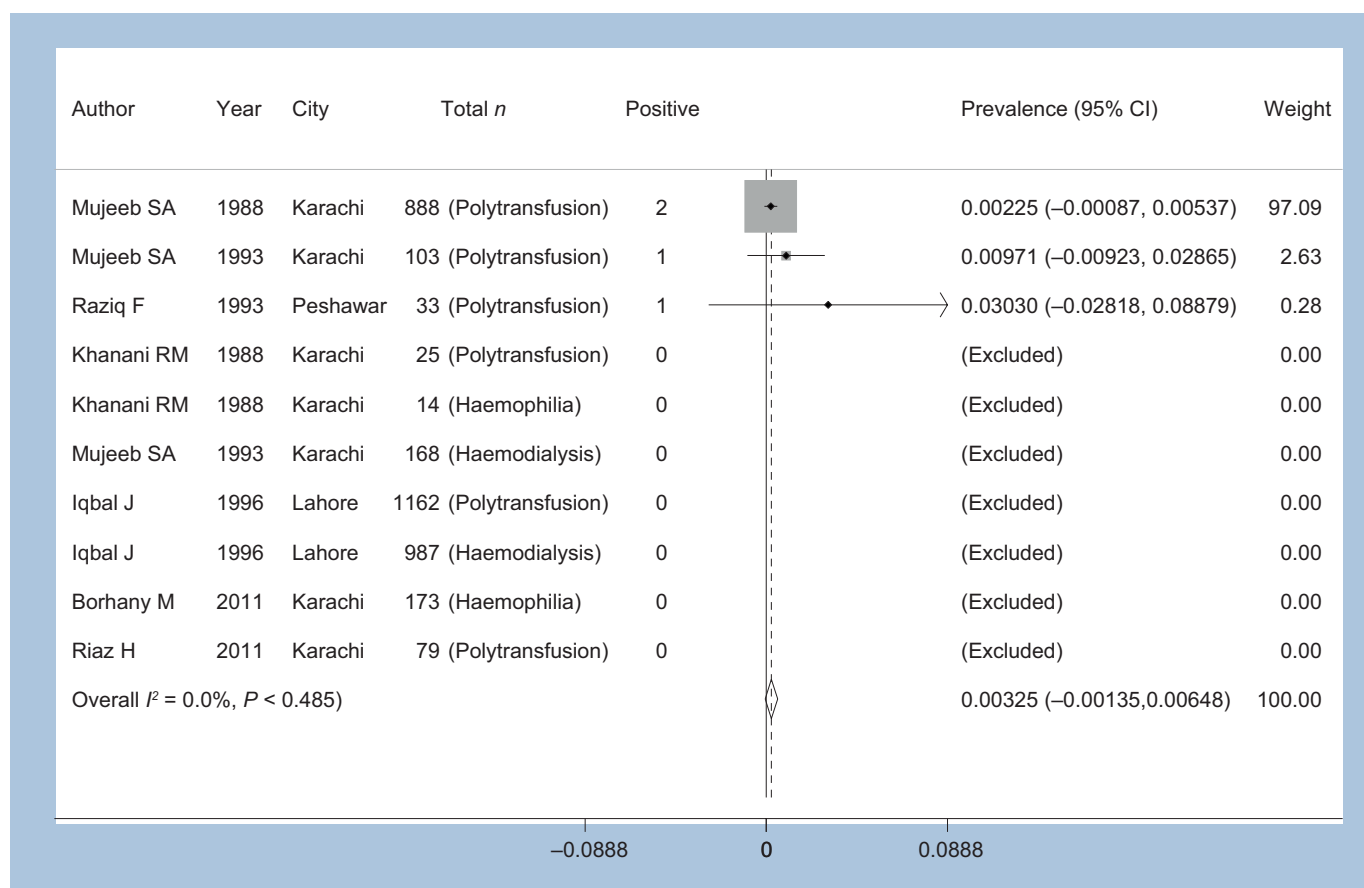


Figure 2: Prevalence of HIV positivity in blood recipients in Pakistan

Forest plot showing prevalence (%) estimates (black solid diamonds) with 95% confidence intervals (bars). Shaded boxes denote the weight allocated to each study based on sample size. The pooled prevalence estimate is represented by the open diamond.

had non-availability of HIV kits for periods of 1–12 months. The same report documented the pooling of blood samples for HIV screening in four blood banks. The methodology was predominantly rapid qualitative assay, adopted by 44/63 or 70% of blood banks, while ELISA was utilized in 15/63 or 24% of blood banks. Four banks were not screening for HIV at all. It was also noted with concern that only two of the 63 surveyed blood banks had a standard operating procedure for HIV testing, while only one addressed the appropriate storage of the kits.

A recent survey report by Kassi et al. showed that 4 (17%) of 23 blood banks were affiliated with either a government or semi-government institution;⁹ 16 (70%) blood banks had a healthy donor recruitment programme and 2 (9%) of the blood banks agreed that they recruited remunerated (paid) blood donors. Donors were screened for HIV in all 23 blood banks.

The authors' institutional blood bank data are comparable to published data from the country. However, the relatively greater seropositivity in voluntary donors and in females may be a consequence of the relatively small population denominator in these cohorts. The trend of HIV seropositivity seemed to be static over a period of years and the overall frequency still appears to be low.

Current situation

Owing to the current geopolitical situation, political turmoil and receding economy, Pakistan spends only 2% of its budget on health. Communicable diseases like hepatitis, malaria and tuberculosis are the top priorities for budget allocation. There is not only a lack of health insurance or medical coverage, but even hospital stays and medications are self-financed. Voluntary blood donations are sparse, and centralized blood banking is non-existent; hospitals are dependent on patients' attendance for their blood supply. Several items of blood-safety legislation were approved during 1997 to 2004 and a national blood policy and strategic framework was laid down in 2008–2014. However, these were never fully implemented. More recently, with the initiatives taken by NBTP in the country, there is hope that the blood-safety system will be reformed.

Strengths and limitations of this study

The study provides a comprehensive review of HIV seroprevalence in Pakistani blood donors in the past 25 years. It gives an insight into a very low risk of transfusion-transmitted HIV in the country at present. However, the studies are not representative and reflect only a small proportion of

the blood that is used clinically in Pakistan. Moreover, nothing is known about the blood banks that are dependent on paid/professional donors for their blood supply. Since females are underrepresented in blood donation, their HIV seroprevalence remains unknown. Similarly, there is no sustainability in the performance of public-sector blood banks, as the HIV kits may periodically be missing. The review was limited by the variation in the type of studies, patchy information, and lack of standardization in the methodologies. The number of blood recipients studied was too small to draw any conclusive result.

Future directions

With cooperation of the Government of Germany, regional blood centres are being established, while blood banks that already exist are reformed.² Regional blood centres will be centrally monitored, with strict overall quality management and HIV surveillance. There is an urgent need to utilize the existing national HIV surveillance data to prevent the spread of HIV.⁵¹ HIV-reactive donors should be notified to a central authority and the tracking system should disallow subsequent donation. Motivation of non-remunerated blood donors is a key concept that underlies safe blood transfusion,⁵² and is one of the initiatives launched by WHO in 2004. The guidelines for blood transfusions developed by NBTP need to be implemented to avoid unnecessary transfusions.⁵³ This would use evidence-based practice to drive the transfusion practices of Pakistan's physicians/surgeons.⁵⁴ Serious gaps in knowledge about HIV have been identified in young people,^{55–57} including medical students.⁵⁸ Nonetheless, media can be used as an effective tool for mass education about HIV/AIDS,⁵⁹ and the medical personnel involved should insist on fully screened blood for their patients and avoid purchasing blood from unregistered blood banks.

Conclusion

At present, the published literature indicates a low risk of HIV transmission through transfusion of blood products in Pakistan. The data are minimal and patchy, with wide variation in methodologies that lack standardization. The low prevalence detected could also be highly significantly confounded by social and cultural factors. Thus, there is an urgent need for a national HIV surveillance system of blood donors and recipients, to elucidate the true magnitude of the HIV burden.

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Feasibility of implementing an integrated tool for improvement of treatment quality and early-warning indicators for HIV drug resistance: a pilot study of centres in India

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ABSTRACT

With the rapid scale-up in use of antiretroviral therapy (ART), monitoring the quality of care and factors that may lead to emergence of HIV drug resistance (HIVDR) is an important focus point for programme managers. The National AIDS Control Organisation of India embarked on strengthening the ART programme for continuous quality improvement (CQI), using defined quality-of-care indicators (QCIs), including World Health Organization (WHO) early-warning indicators (EWIs) for HIVDR. In this feasibility study, done during July 2014, an integrated QCI and EWI tool developed by WHO India was pilot tested across 18 purposively selected ART centres. At seven ART centres, the EWI 1 target of >90% on-time pill pick-up was achieved for adult patients, while among the paediatric age group (<15 years old) it was not achieved by any centre. EWI 2 (retention of patients in ART care at 12 months after initiation) showed that two centres had retention of both adult and paediatric patients of >85% at 12 months of ART, while 11 centres had retention between 75% and 85%. EWI 3 (pharmacy stock-out) for adult and paediatric patients showed that 11 ART centres reported a minimum of one stock-out for the first-line ART drugs in the reporting period, while EWI 4 targets (pharmacy dispensing practices) were achieved by all the centres, for both adults and children. Average retention in care at 6, 12 and 24 months after ART initiation was 82%, 77% and 71%, respectively. This feasibility study showed that EWI analyses were much simpler to conduct if information was sought only for patients receiving ART, for whom the quality of record-keeping is better and more consistent. The activity has highlighted the need for improved quality of record-keeping at the facilities and implementation of specific interventions to ensure better patient follow-up. After modifications, use of the tool will be phased in across all the ART centres in India.

Key words: antiretroviral therapy (ART), early-warning indicators, HIV drug resistance (HIVDR), India

BACKGROUND

The free Indian antiretroviral therapy (ART) programme established in 2004 at eight clinics has been scaled-up to provide treatment to approximately 8 94 000 people across 516 ART centres and 900 link ART centres within the public sector, as of August 2015.¹ Every year, nearly 100 000 additional people living with HIV (PLHIV) initiate ART. The programme projects that about 1.25 million PLHIV will be receiving treatment by March 2017. With this high level of scale-up,

monitoring the quality of care and factors leading to emergence of HIV drug resistance (HIVDR) is of paramount importance for the programme.

The World Health Organization (WHO) has developed a set of standard early-warning indicators (EWIs) that are used as indirect markers for assessing the emergence of HIVDR.² Common factors associated with the emergence of HIVDR include inappropriate treatment regimens; ART drug stock-outs; and poor adherence to treatment – monitored through

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five core EWI indicators: on-time ARV pill pick-up (EWI 1); retention of patients in ART care at 12 months after initiation (EWI 2); pharmacy stock-out (EWI 3); pharmacy dispensing practices (EWI 4); and virological suppression 12 months after ART initiation (EWI 5).³ WHO recommends that these indicators be collected annually at each ART centre or from a selected representative sample. For each EWI indicator, minimum performance targets are recommended. An Excel-based (Microsoft, United States of America) tool has been developed by WHO to facilitate collection of EWIs by countries.⁴

In 2014, India embarked on a continuous quality-improvement (CQI) mechanism using selected quality-of-care indicators (QCIs) and the EWIs listed above. Selected QCI indicators like retention in care (On-ART and Pre-ART retention cascade), regularity of CD4 testing (On-ART and Pre-ART), and timely ART initiation among eligible patients (defined as within 60 days from the date the patient is eligible for treatment), which are deemed critical for monitoring the quality of patient care, were identified by the national programme. A pilot study with the support of the WHO Country Office for India and the United States Centers for Disease Control and Prevention (US CDC) was implemented to assess the feasibility of conducting the QCI/EWI activity across the country. This paper presents the results of this pilot study and focuses on data-collection and methodology concerns and lesson learnt for planning purposes.

APPROACH TO THE ASSESSMENT

Using WHO recommendations on prevention and surveillance of HIVDR,^{5,6} and the WHO *Metrics for monitoring the cascade of HIV testing, care and treatment services in Asia and the Pacific*,⁷ key indicators useful for monitoring the quality of ART services and EWIs that could be collected in India were selected. A purpose-built tool was constructed to include WHO EWI- and additional ART programme-specific QCIs (see Table 1). Country-specific adaptations to the WHO EWI tool included ART drugs used in the programme and possible reasons for patients not being retained in care. For EWI 2, data were extracted from the QCI tool. The QCI tool was

developed to enable easy and quick extraction of data from a retrospective cohort analysis of a sample of patients receiving treatment and in pre-ART care, for 12 and 24 months. Primary records used for data extraction include the individual patient treatment record, ART enrolment register, pre-ART register and drug-dispensing register. EWI 5 was not reported because no information on this indicator is available, since testing of viral load is not done routinely in the programme and no information on viral load is available for patients on first-line ART. Data for all the indicators in this activity were abstracted from existing routinely collected medical records at the ART centres; hence, ethical review was not deemed necessary but the required administrative approvals were obtained from the National AIDS Control Organisation of India.

A section for qualitative entries such as impending drug stock-out, or other factors influencing programme implementation was included to better interpret the information collected. Similar to the WHO EWI Excel tool, which incorporates error-checks, the QCI tool uses Excel functions to flag data-entry issues. The tools also provide automated generation of analysed results as data are entered.

Calculation of the sample size underlying the number of records to be extracted from sites was based on the WHO EWI guidelines, which provide sample sizes with a 95% confidence interval.³ For all EWIs and QCIs, adult and paediatric patients were sampled separately. The number used for generation of the minimum sample size was the actual number of patients alive and on ART as on 31 March 2014. Individual patient records were then consecutively sampled, starting from 1 April 2013 onwards (as per the start of the activity-reporting period), until the minimum sample size was reached.

For the QCI On-ART and Pre-ART cohorts, the number of patients registering at the clinic and initiating ART between 1 April 2012 and 31 March 2013 was used to calculate the minimum cohort size. Patient records were sampled starting from 1 April 2012 (as per the start of the activity-reporting period), consecutively until the minimum sample size was reached.

Table 1: Quality-of-care indicators

QCI	What it measures	Results
QCI 1: % retention on pre-ART care at 12 and/or 24 months	% of patients enrolled at ART centre that are still alive and in pre-ART care	Retention on pre-ART care at 12 months: 13% Retention on pre-ART care at 24 months: 7%
QCI 1a: % retention on ART care at 12 and/or 24 months	% of patients enrolled in ART care who are still alive and on ART	Retention on ART care at 12 months: 77% Retention on ART care at 24 months: 71%
QCI 2: CD4 counts at time of enrolment in HIV care and within pre-ART follow-up	Immune function at enrolment and regularity in CD4 testing during follow-up within HIV care (Pre-ART cohort)	CD4 counts recorded at baseline: 97% CD4 counts recorded at 12 months: 74%
QCI 2a: CD4 counts at time of ART initiation and follow-up in ART care	Immune function at ART start and regularity in CD4 testing during follow-up (ART cohort)	CD4 counts recorded at start of ART: 99% CD4 counts recorded at 12 months from start of ART: 78%
QCI 3: % of patients starting ART within 60 days of eligibility determination	Appropriate and timely start of ART: data from pre-ART and ART cohorts	88%

ART: antiretroviral therapy; QCI: quality-of-care indicator.

The study period for the pilot exercise was 1 April 2013 to 31 March 2014; hence, the start dates for sample abstraction were defined accordingly. The exercise was carried out at 20 purposively selected ART centres (with good record-keeping and adequate human resources in place), including 10 centres of excellence. Hands-on training on the tool was conducted with medical officers and data managers from all these centres. After training, they were given 15 days to complete the exercise. National trainers were in continuous contact, to support implementation. Reports were checked and validated by the national team and interpretation of results was done by programme managers at the national level. To check for correctness of entries in the tools, ART centres were randomly visited by programme managers, and records at the ART centres were compared with the entries made in the tools. In case of discrepancy, the centres were asked to re-submit the completed tools.

OBSERVATIONS ON FEASIBILITY

A total of 3365 adult and 1394 paediatric patients were entered in the EWI tool that was implemented at 18 ART centres. Owing to programmatic reasons, two centres were not able to submit reports in time for their data to be included in this analysis. Of the total ART centres that reported, seven had EWI 1 (adult) >90%, while eight had EWI 1 (paediatric) between 80% and 90%. For the paediatric cohort, no centre had

EWI 1 >90%. Results of EWI 2 (adult and paediatric combined) showed that two centres had retention of more than 85% at 12 months of ART, while 11 centres had retention between 75% and 85%. Results for EWI 3, which monitors drug stock-out, showed that the majority of centres (i.e. 11) had experienced stock-out for at least one ART drug in the 12-month reporting period (i.e. 1 April 2013 to 31 March 2014). No centre reported using mono or dual therapy (EWI 4) for adult or paediatric patients (see Table 2).

QCI results for 2771 adult patients on ART revealed that the median duration for ART initiation from the time of eligibility was 16 days; 88% of the patients were initiated on ART within 60 days of becoming eligible for ART initiation. The median CD4 count at the time of ART initiation was 204 cells/mm³ and 49% patients were classified as WHO stage 1 or 2. For adults, retention in care at 6, 12 and 24 months after ART initiation was 82%, 77% and 71%, respectively.

There were 137 children aged <15 years sampled in this cohort who initiated ART on or after 1 April 2012; 91% of all children were started on ART within 60 days of ART eligibility, which is above the optimal time for this QCI indicator (at 90%). The median CD4 count at the time of start of ART was 744 cells/mm³. Among children aged <5 years, 80% had CD4 counts at baseline of <1000 cells/mm³, while among children aged >5 years, 82% had counts of ≤500 cells/mm³ at the time of ART initiation.

Table 2: Results of early-warning indicators (adult and paediatric patients)

EWI	Performance targets	Number (%) of ART centres ^a
EWI 1 Adult (on-time pill pick-up) ^a	<80%	6 (33%)
	80–90%	5 (28%)
	>90%	7 (39%)
EWI 1 Paediatric (on-time pill pick-up) ^b	<80%	6 (43%)
	80–90%	8 (57%)
	>90%	0
EWI 2 Adult ^a and paediatric ^b (retention in care)	<75%	5 (28%)
	75–85%	11 (61%)
	>85%	2 (11%)
EWI 3 Adult (pharmacy stock-out) ^a	<100%	11 (61%)
	100%	7 (39%)
EWI 3 Paediatric (pharmacy stock-out) ^c	<100%	11 (73%)
	100%	4 (27%)
EWI 4 Adult (pharmacy dispensing practices) ^a	>0%	0
	0%	18 (100%)
EWI 4 Paediatric (pharmacy dispensing practices) ^c	>0%	0
	0%	15 (100%)

ART: antiretroviral therapy; EWI: early-warning indicator.

^a Number of ART centres reported = 18.

^b Number of ART centres reported = 14.

^c Number of ART centres reported = 15.

Pre-ART QCI cohort analysis on 3138 records showed that 49% were in WHO stage 1 at the time of registration in care. Sixty-eight per cent of adult patients had a CD4 count below 350 cells/mm³ at the time of registration, and, of these, 79% were started on ART within 30 days of registration.

LESSONS LEARNT AND FUTURE PLANS

India is one of the first countries in the WHO South-East Asia Region to pilot an integrated EWI and QCI tool for both On-ART and Pre-ART cohorts. The key objective of piloting the integrated QCI and HIVDR EWI monitoring tool was to assess the feasibility of this activity in a large country like India. Valuable lessons were learnt in implementing the tool at national and facility levels. As the pilot exercise involved extracting data for three separate components (EWI, QCI-On-ART cohort and QCI-Pre-ART cohort), much time was taken from other duties for clinical staff at the facility. At high-load treatment sites, up to 600 records needed data extraction. In order to complete the exercise, staff required at least 3–4 days to complete the EWI tool, and another week to complete the On-ART and Pre-ART cohort analysis up to 12 and 24 months. In terms of data management and analysis, EWI analyses were much simpler, as information was sought only for On-ART patients, for whom the quality of record-keeping was better and more consistent. As the cohorts were constructed with multiple time-points and outcomes, data cleaning and analysis was complex and labour intensive.

The pilot tool included several indicators common to both the Pre-ART and On-ART cohort, such as “timely initiation of ART”, which could result in duplication. For the On-ART cohort, this indicator was assessed using the ART treatment register and record, which is better maintained. The same information was also extracted for the Pre-ART cohort using the Pre-ART register; however, there was more variability of data quality in this register. The pilot study therefore highlighted the collection of Pre-ART data as an area requiring focused strengthening.

Having results readily available with data entry was an important factor motivating staff in completing the exercise correctly. The tools had inbuilt auto-generated results. Staff felt that these quick results were helpful in overviewing centre performance and delineating the profile of their patients, and helped to provide a baseline to improve services.

Support to facilities for implementation was critical. Several centres could not follow the guidelines for sampling and sample-size calculation, despite training and mentoring, e.g. sampling from the wrong time-point, e.g. April 2013 instead of April 2012; and using incorrect numbers for calculation of the minimum sample size, e.g. patients “ever initiated” on ART instead of “patient initiating ART in a specified time-period”. The need to strengthen training was a key lesson learnt from this pilot study and more-comprehensive training has been introduced as a result. Other common problems included incomplete data, such as non-completion of the facility profile, which limited interpretation of results, particularly for drug stock-outs. In this situation, where the programme institutes

strategies to prevent impending drug stock-out, e.g. short refills of drugs for 1–2 weeks instead of monthly supplies, these instances can only be added as qualitative information.

In addition, in some cases, staff applied their judgement on the outcome status of patients when they had not completed the full cohort follow-up period in order to complete the exercise, e.g. entering the status of a patient at 24 months even if they had been in care only for 18 months. Data-entry error such as entering patients into the Pre-ART cohort even after they have started receiving ART led to misclassification errors.

The results from this activity bring out similar concerns to those that have been highlighted in EWI-monitoring studies conducted in other countries. Namibia has collected EWIs using the 2010 WHO EWI definitions, which predated the definitions used in this study,⁸ wherein 52% of the sites had loss to follow-up at 12 months of $\leq 20\%$, while the EWI 3 target was achieved by 67% of the clinics.⁹ In South Africa, a study comparing results from two clinics showed that clinic A achieved the targets for EWI 2 and EWI 4, while clinic B could only achieve the target for EWI 3 (EWI 5 not done).¹⁰ Another study conducted in Malawi showed that retention at 12 months of $>70\%$ was achieved by 38% clinics.¹¹ In the present study conducted in India, a significant proportion of ART users did not meet the WHO targets for EWI 1, i.e. on-time pill pick-up, and EWI 2, i.e. retention of patients in ART care at 12 months after initiation. The results of EWI collection in India show that stock-out of ART drugs was an issue in 2014. The areas that require more focus are better adherence monitoring for ART, patient follow-up, and strengthening the ART supply chain. Monitoring the overall adherence of patients on ART through tracking EWI 2 is easier than measuring individual patient-level adherence, a practice that is now widely adopted, especially in countries with a large number of facilities.¹²

Lastly, a common concern of the majority of data abstractors was incomplete records at the facility, with inadequate information in both the registers and individual patient records, necessitating triangulation from multiple sources, a problem that was also reported by other countries that have conducted this activity.^{9,10} For every patient record abstracted, two to three other data sources were needed. This experience was important for mentoring and supervision of not only centres, but also clinical staff participating in this exercise, on the need for correctness, completeness and consistency across different monitoring and evaluation tools at facilities. Work to rectify the challenge of incomplete data recording has been initiated.

One of the limitations of this study is that, since the centres were purposively selected, the results are not representative. Moreover, two of the 20 selected centres were unable to submit reports on time and so the monitoring at these facilities is not recorded here. An important follow-up of this pilot has been simplification of the two tools and development of a comprehensive hands-on training curriculum, besides ensuring that the participants understand the importance of this activity.

The pilot exercise to extract EWIs and QCI indicators has helped understanding of not only the performance of ART facilities in terms of these outcomes, but also the capacity of staff and the

quality of the recording and reporting system. Having quick and immediate feedback through auto-generated results of the exercise motivates staff and provides data for improvement of local services by the facility team. An annual exercise will give trends on the quality of care delivered by ART sites. In order to keep the workload manageable, the tool will be further simplified and minimized to the EWI and QCI On-ART cohort analysis. This decision keeps in view that almost all patients registering in care will require ART initiation, as the CD4 thresholds for ART initiation increase in the programme. Pre-ART cohort analysis will be conducted as special studies in selected sites, in order to get information about Pre-ART retention, etc. QCI/EWI collection and analysis has highlighted the areas that require immediate ART programme strengthening in order to limit HIVDR and improve survival. Results of this pilot demonstrate that WHO HIVDR EWI and QCI monitoring can be used to assess the strengths and weaknesses of ART programmes and guide managers and implementers at state and national level on strategies to resolve and strengthen identified areas of weakness. Factors responsible for not meeting targets should be analysed by the National AIDS Control Organisation of India (programme managers) at each site (ART centres), as part of the ART quality-improvement process, in order to identify the most appropriate recommendations. In order to ensure sustainability, this exercise will be incorporated into the Strategic Information Management System (SIMS), as part of routine programmatic monitoring and evaluation across all ART facilities in the country, and will be useful during the state, regional and national-level review meetings.

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Impact of rubella vaccination on elimination of congenital rubella syndrome in Sri Lanka: progress and challenges

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ABSTRACT

Rubella infection in pregnancy can lead to pathologies, including miscarriage, stillbirth and congenital rubella syndrome (CRS) in the neonate. Rubella vaccination can prevent all occurrences of CRS. In Sri Lanka, significant outbreaks of CRS occurred in 1994 and 1995, with 275 and 212 reported cases. In 1996, Sri Lanka introduced rubella vaccination for women aged 16–44 years, to stop CRS. Measles–rubella vaccine was introduced into the routine immunization schedule in 2001 and additional campaigns were carried out in 2003 (all 11–15 year olds) and 2004 (all 16–20 year olds). Reported immunization coverage with a single dose of a rubella-containing vaccine has been more than 95% since 2000. Laboratory-supported surveillance for rubella and CRS was started in 1992. Reported rubella cases fell from 364 (incidence 19/million population) in 1999 to 96 cases (incidence 5/million population) in 2002 and further to 12 cases (incidence 0.6/million population) in 2014. Laboratory-supported CRS surveillance was started in 1990 and the highest number of CRS cases, 275 (incidence 77/100 000 live births), was diagnosed in 1994. Reported CRS cases fell from 22 cases (incidence 7/100 000 live births) in 2002 to 3 cases (incidence <1/100 000 live births) in 2014. Almost 20 years of routine rubella vaccination has resulted in >96% reduction in reported rubella cases and a corresponding >98% reduction in CRS cases. Despite this great achievement, work remains to eliminate rubella and CRS from Sri Lanka.

Key words: congenital rubella syndrome, elimination, rubella-containing vaccine, rubella vaccination, Sri Lanka

BACKGROUND

Rubella infection in pregnancy can lead to pathologies, including miscarriage, stillbirth and congenital rubella syndrome (CRS) in the neonate, particularly during the first trimester of pregnancy. Widespread epidemics are still experienced in some low- and middle-income countries, despite extensive worldwide vaccination efforts.^{1,2}

Evolution and identification of disease entities and descriptions of CRS began in 1752 and intensified with the experience of a major pandemic in 1963. Global attention on epidemiological studies describing correlates and identification of the rubella virus in CRS led to the development of a preventive vaccine during the late 1960s. By 1996, only 83 Member States of the World Health Organization (WHO) had introduced a rubella-containing vaccine (RCV) aiming at CRS control; however, there has subsequently been a steady increase in the number of countries introducing rubella vaccination.^{2,3}

Rubella has been described as a periodic disease with epidemics occurring every 5–9 years, and the incidence of surveillance-detected cases varying from 0.8 to 4/1000 live births during epidemics to 0.1–0.2/1000 live births during non-epidemic periods.³ By the end of 2009, 130 WHO Member States had introduced RCV into their national immunization schedule, including four of the 11 Member States in the WHO South-East Asia Region.³

CRS was estimated to have affected 22 000 babies in 1996 in Africa, 46 000 in South-East Asia and nearly 13 000 in the Western Pacific. Very few countries in these regions introduced RCV between 1996 and 2008, so a significant reduction of the disease burden of rubella and CRS was not expected over this time.⁴

In September 2013, the WHO Regional Committee for South-East Asia adopted resolution SEA/RC66/R5, with the goal of eliminating measles and achieving control of rubella/CRS by

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2020.⁵ In 2014, the South-East Asia Regional Immunization Technical Advisory Group (SEAR-ITAG) reported that they were encouraged by the commitment of countries to this regional goal and by their efforts to put in place the necessary programme components to achieve this goal, including building laboratory capacity, developing systems to conduct case-based reporting, and implementing data-feedback mechanisms.⁶

Substantial progress in control of CRS has been achieved in Sri Lanka, with the introduction of rubella vaccination into the national immunization programme since 1996, leading to a marked decline of CRS-related morbidity and mortality. The national elimination plan was revised in September 2015 and sets elimination targets of <1 rubella case/million population and zero CRS cases/100 000 live births by 2020. Rubella and CRS surveillance have been intensified to achieve the revised targets by 2020.⁷ Against this background, the country is working towards elimination of rubella and CRS; detailed guidance will be published in January 2016. This paper summarizes country activities in Sri Lanka to date, the current situation regarding CRS, prospects for elimination of CRS, and the way forward to achieve the goals for elimination of CRS.

PRACTICES AND PERSPECTIVES IN ELIMINATION OF CONGENITAL RUBELLA SYNDROME

Rubella vaccination policy

Vaccination of women of reproductive age (16–44 years) against rubella has been started as a national policy and has been included in the National Expanded Programme on Immunization (EPI) in Sri Lanka since 1996, based on the evident CRS epidemics in 1994–1995 (see Tables 1 and 2). Through the National EPI, one dose of monovalent measles vaccine had been given routinely at the age of 9 months since 1984, but a requirement to introduce a second dose was identified after a measles outbreak in 1999–2000. This gave an opportunity to introduce a combined measles–rubella (MR) vaccine into the National EPI, and in 2001 MR vaccine was introduced for all children at the age of 3 years, through the National EPI.⁸

In 2011, a National EPI policy decision was taken to introduce measles–mumps–rubella (MMR) vaccine to the EPI. The MR vaccine given at the age of 3 years and measles monovalent vaccine given at the age of 9 months were replaced with MMR vaccine given at 1 year of age, but this was rescheduled in 2015 to be given at 9 months. Currently, all children aged 9 months (birth cohort of around 350 000) and 3 years receive MMR vaccination.^{8,9}

Supplementary immunization through catch-up vaccination campaigns conducted in 2003 among individuals aged 10–15-years (coverage of 95%) and in 2004 among those aged 16–20 years (coverage 72%) with MR vaccine further contributed to the development of population immunity to rubella.^{8,10}

In addition, school-based adolescent rubella vaccination has been given at the age of 14 years since 2002, initially for girls only. Boys aged 14 years were included in 2004 and this strategy continued until 2012, then stopped once all children who had received MR vaccine at the age of 3 years in 2001 had reached 14 years.⁸

Since 2000, field health-care staff ask all women of reproductive age for their history of rubella vaccination at community level, when a new couple starts their family life and is registered onto the “Eligible Couple Register”. If the field health-care staff find anyone who has not been vaccinated, they ensure they are vaccinated for rubella at that time.

Standards for surveillance of rubella/ congenital rubella syndrome

Rubella and CRS have been identified as notifiable diseases by the Government of Sri Lanka and notification has been mandatory since 1996.¹¹ Rubella antibody testing was continued during the 1990s and specific rubella immunoglobulin (IgM) testing, with follow-up of individuals with elevated titres, was established at the Virology Laboratory after 1990. During the period 1994–1995, an increased number of CRS cases were detected at the laboratory and by clinicians, following an outbreak of rubella; the College of Paediatricians was involved in a special survey (combined retrospective and prospective)

Table 1: Rubella vaccination policy in Sri Lanka, 1996 to present

Year	Vaccine	Target group(s)
1996 EPI	Rubella	Women aged 16–44 years
2001 EPI	MR	All children aged 3 years
2002 (EPI)	MR	14 years (girls first and all after 2 years)
2003 Catch-up campaign	MR	10–15 years (95% coverage)
2004 Catch-up campaign	MR	16–20 years (72% coverage)
2011 EPI	MMR (replacing Measles at 9 months and MR at 3 years)	
	MMR1 advanced to 1 year of age in 2011 and re-scheduled to 9 months in 2015; MMR2 at 3 years of age	

EPI: Expanded Programme on Immunization; MMR: measles–mumps–rubella combined vaccine; MR: measles–rubella combined vaccine.

Table 2: Cases of rubella and congenital rubella syndrome from 1991 to 2014

Year	Rubella			CRS				
	Clinical cases of rubella	Laboratory-confirmed rubella	Birth cohort	Suspected cases of CRS investigated	Laboratory-positive cases	Diagnosed CRS	CRI	Discarded
1991	—	4	—	659	3	3	—	656
1992	—	—	—	12 ^a	12	12 ^a	—	0
1993	—	35	—	1142	86	10 ^a	—	1132
1994	—	221	356 071	2069	89	275 ^c	—	1848
1995	87	214	342 224	1632	81	212	—	1418
1996	138	37	340 649	1847	59	143	—	1704
1997	115	63	333 219	2070	17	115	—	1955
1998	132	NA	322 672	NA	26	136	—	—
1999	364	44	328 725	2655	45	155	—	2500
2000	122	14	347 749	2232	25	27	—	2205
2001	146	15	358 583	2258	15	15	—	2243
2002	96	12	367 709	2206	22	22	—	2184
2003	101	42	367 064	1092	6	6	—	1086
2004	54	NA	364 711	NA	19	19	—	—
2005	156	NA	370 731	NA	5	5	—	—
2006	89	NA	373 538	1630	1	1	—	1629
2007	55	NA	386 513	1495	4	4	—	1491
2008	35	94	379 912	1827	2	2	—	1825
2009	27	26	376 843	871	3	0	3	868
2010	65	22	364 565	1037	5	3	2	1032
2011	438 ^b	142	363 492	907	4	4	—	903
2012	61	19	355 900	1366	18	12	2 (2 remained untraceable)	1352
2013	24	20	365 524	1181	5	5	—	1176
2014	12	10	349 715	1168	4	3	1	1164

CRI: congenital rubella infection; CRS: congenital rubella syndrome; NA: could not identify exact numbers from available information.

^aLaboratory-confirmed cases only.

^bSince this was during an outbreak, only five cases from each locality were laboratory confirmed.

^cPaediatricians' survey data.

and identified 275 clinical cases of CRS (103 were laboratory confirmed) in 1994, and 169 cases of CRS in the first 4 months of 1995, with a total of 212 for the whole of 1995.⁸

Since 1996, a routine system has been used to notify all suspected cases of rubella and CRS, from all health-care

institutions, to the medical officer of health of the patient's residential area, who is responsible for community-level health care of the people. Any infant with a history that is compatible with the specified case definition for CRS surveillance, which is "maternal history of rubella infection and/or with signs and symptoms from any of cataract/congenital glaucoma,

pigmentary retinopathy, congenital heart disease, loss of hearing or purpura, splenomegaly, jaundice, meningo-encephalitis, microcephaly, mental retardation, radiolucent bone disease or laboratory rubella IgM-positive result”, is notified and a detailed case-based investigation is conducted. Details of CRS cases investigated in the field are compiled weekly and reported to the Epidemiology Unit, Ministry of Health, together with case-based field-investigation reports. Rubella notification also follows the same routine surveillance system but notifications are based on surveillance case definitions given in the national *Surveillance case definitions for notifiable diseases in Sri Lanka* for rubella and for measles.¹¹

Further, the field-level medical officers of health have developed good working relationships with the private health sectors and receive their notifications of rubella and CRS. All reported cases are compiled and reported to the Epidemiology Unit surveillance system on a weekly basis, and the completeness and timeliness of the information reported is regularly monitored.

In addition, if the field-level public health midwife who provides house-to-house domiciliary care identifies any suspected cases of rubella or CRS at household level, they report them to their relevant field-level medical officer of health for further investigations, reporting, preventive measures and follow-up. It is expected that all suspected cases of rubella and CRS are tested at the laboratory for rubella IgM for case confirmation.

In Sri Lanka, nearly 100% of births occur in health institutions, and over 90% take place in institutions with specialists available. More than 90% of patients attend conventional (rather than traditional) health facilities,¹² where the majority of CRS cases are notified. Active surveillance and zero reporting has been added since 2004, including all these health-care institutions as sentinel sites in which medical specialists are available. These sentinel-site hospitals have identified surveillance in-charge officers who actively look for cases and report weekly to the Epidemiology Unit, Ministry of Health. In the absence of cases, essential zero reporting ensures the comprehensiveness of reporting. The completeness and timeliness of weekly reporting from sentinel sites is closely monitored.

A blood sample is collected from patients on obstetric wards, for TORCH (toxoplasma, rubella, cytomegalovirus and herpes) screening, if the maternal history is suggestive of a risk of exposure to possible rubella infection or babies are born with congenital abnormalities. These samples are sent to the Virology Laboratory at the Medical Research Institute, Ministry of Health, where they are tested for specific antibodies. Babies who are positive for rubella IgM are identified and reported to the National Surveillance System at the Epidemiology Unit, Ministry of Health and followed up for rising antibody titres. The Epidemiology Unit is the main unit that is nationally responsible for surveillance of rubella/CRS and compiles information received, compares the compatibility of observations and test results, and finally classifies cases for CRS, congenital rubella infection (CRI) or discard.

Case classification

Case classification is conducted in accordance with the regional guidelines for case classification of CRS,¹³ which are described as list A (cataract, congenital glaucoma, congenital heart disease, loss of hearing and pigmentary retinopathy) and list B signs (purpura, splenomegaly, microcephaly, mental retardation, meningo-encephalitis, radiolucent bone disease and jaundice within 24 h of delivery). A clinically compatible CRS case that has at least two symptoms from list A or one from list A and one from list B is considered as a CRS case. If such a case has an IgM-positive laboratory report, it is considered as a laboratory-confirmed CRS case. All other infants with no clinical signs of CRS but who have a positive rubella-specific IgM test, will be classified as CRI. Cases suspected but not compatible with CRS or CRI are discarded as non-CRS or non-CRI cases.

THE SITUATION OF CONGENITAL RUBELLA SYNDROME IN SRI LANKA 2002–2012

Data sources

As it is the national focal point for routine surveillance of communicable disease, the Epidemiology Unit received all compiled data on notified rubella and CRS on a weekly basis through the “Weekly Return of Communicable Diseases” (WRCD), which were entered into the national database.

Weekly reporting from sentinel sites of rubella and CRS cases were maintained on separate databases and the data entered were used to assess the compatibility of numbers reported, to identify individual cases and to exclude duplicates.

Case-based special surveillance was done routinely at the field level for all clinically compatible rubella and CRS cases, and forms that were received were analysed for case identifications and final classifications. All CRS cases identified and tested at the laboratory were used to identify the final results.

Clinicians, including those from specialized units (ophthalmology and cardiology), identified around 1000–1500 suspected cases per annum (including samples for TORCH screening) and tested these for rubella at the National Virology Laboratory. All babies who tested positive for rubella antibody (IgM) have been routinely traced back since 2008, to identify CRS cases and ensure detailed case-based investigations for final case classification.

In the preparation of this paper, the authors were permitted to extract reported information on rubella and CRS cases, as well as laboratory test results from the Ministry of Health’s national databases.

Observations

The completeness of reporting of weekly reports of rubella and CRS has been regularly monitored and maintained at around 90–100% for more than a decade by the National

Communicable Disease Surveillance Programme of the Epidemiology Unit.

Data collected from the National Virology Laboratory and the National Communicable Disease Surveillance Programme were compiled. Population data on birth cohorts, which

were obtained from the Medical Statistics Unit and from the Department of Census and Statistics are presented in Table 2. Continued surveillance information has shown that the incidence of CRS in the country has been maintained at below 1 per 100 000 live births for the last 15 years (see Figs. 1 and 2).

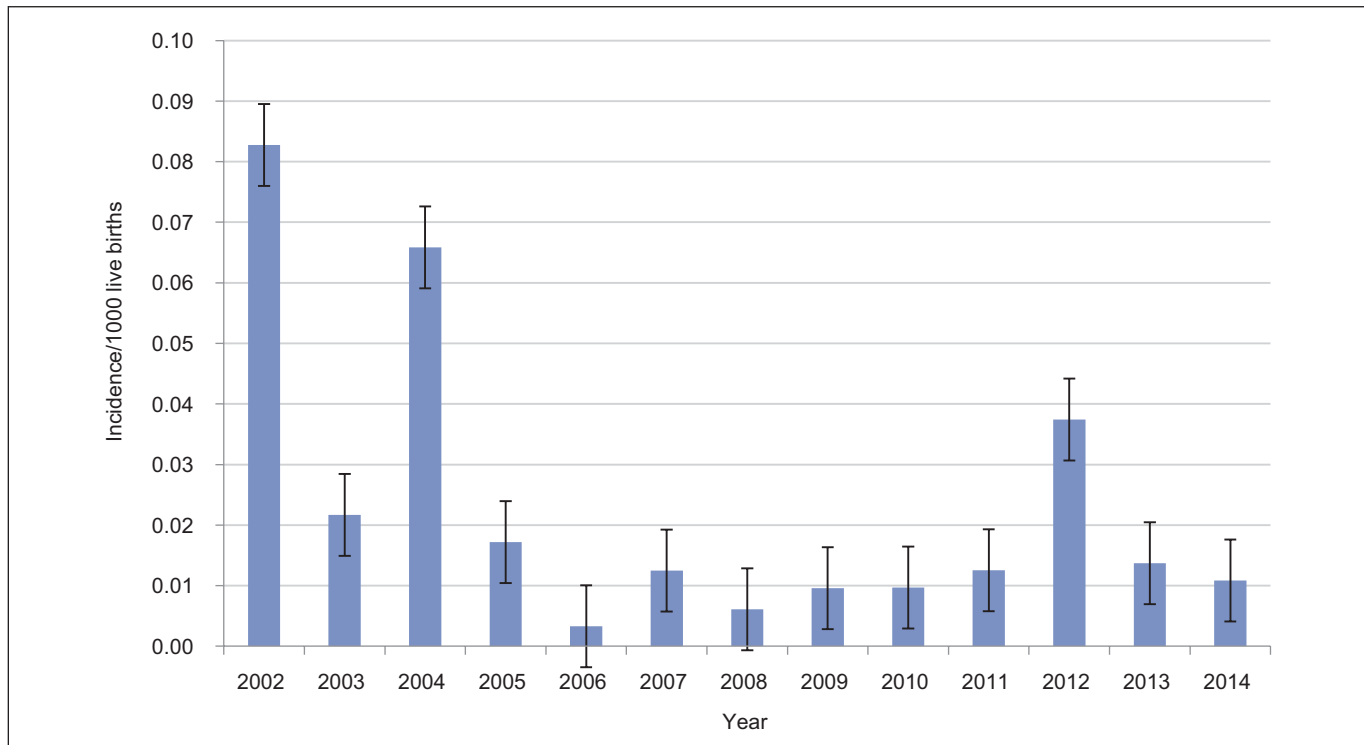


Figure 1: Incidence of congenital rubella syndrome cases by year with 95% confidence intervals

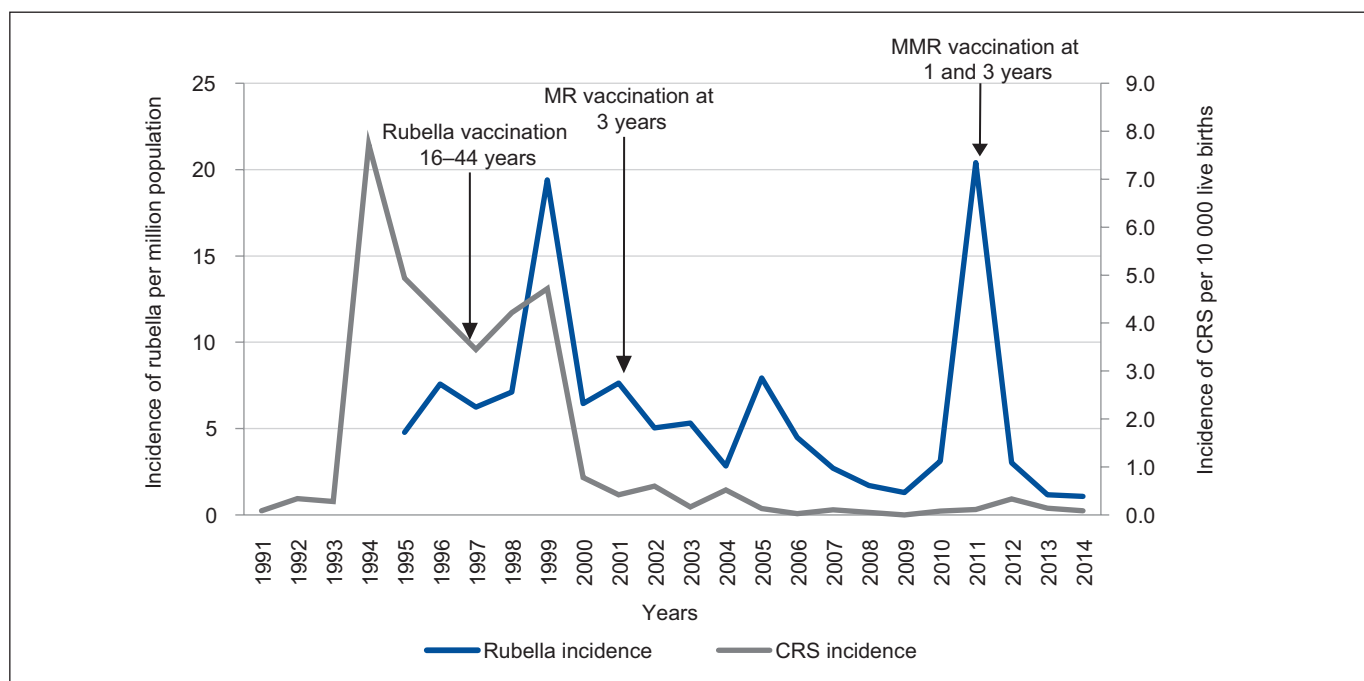


Figure 2: Trend of rubella and congenital rubella syndrome cases

CRS: congenital rubella syndrome; MMR: measles–mumps–rubella vaccination; MR: measles–rubella vaccination.

National coverage of MR (during 2001–2011)/MMR (during 2011–present), as shown in Figure 3, contributes to maintenance of high population-level immunity among children under 15 years of age. High transmission of rubella experienced among adult males during 2011 was probably due to the number of adult males who were still susceptible to rubella, but were expected to be protected by herd immunity at the population level. Adult males still remain susceptible because the first rubella vaccination was introduced only to females of reproductive age (16–44 years) in 1996, and the first exposure of males to rubella vaccination was in 2001 (through EPI at 3 years) and during 2003–2004 (measles catch-up campaign with MR).

All pregnant mothers (367 528 in 2014) were asked for their history of rubella vaccination status at antenatal clinics and routine reporting to the National Maternal and Child Health Programme detected that 98% of pregnant mothers were protected against rubella disease in 2014 (personal communication). A gradual increase in the coverage of rubella protection has been observed over the last 5-year period reported, from 93% in 2008 to 97% in 2013.¹⁴

A sero-survey conducted in 1999 showed a range of 75–92% susceptibility to rubella in children aged 3–13 years, providing research-based evidence for the decision in 2001 to vaccinate all children aged 3 years with RCV, as the best strategy in Sri Lanka to reduce the risk of CRS in the long term.^{13,15}

Case-based CRS investigation of all suspected cases at institutional and field level has been strengthened. If a pregnant mother is found not to have been vaccinated against rubella (without a proper history of documented rubella dose), adequate investigation and follow-up of the baby is done to

exclude possible CRS, and post-partum rubella vaccination is administered to the mother. Close monitoring of the sentinel-site zero-reporting system, CRS surveillance, and laboratory surveillance of rubella infection (IgM) of neonates with any congenital abnormalities is further strengthened by close vigilance that is expected to halt endogenous transmission of rubella.

Recent outbreaks of rubella and congenital rubella syndrome

Sri Lanka experienced sporadic isolated small outbreaks of rubella in 2011. A total of 410 of 438 cases of rubella reported in 2011 were outbreak related (see Table 3); the remaining 28 cases were identified via routine surveillance, and case-based investigations could not identify any relationship with outbreak cases. The majority of reported outbreak cases were adult males and locations were mainly military camps or factories where adult males were in close proximity to each other, making those who had not been immunized through the National EPI more susceptible to infection. Detailed analysis revealed that even though obvious rubella disease was not seen in females, 12 cases of CRS were diagnosed following outbreaks experienced during this period (see Table 3).

STRENGTHENING STRATEGIES FOR ELIMINATION OF CONGENITAL RUBELLA SYNDROME – LESSONS LEARNT

Sri Lanka has already achieved the regional CRS control target of <1 CRS case per 100 000 live births and is progressing well

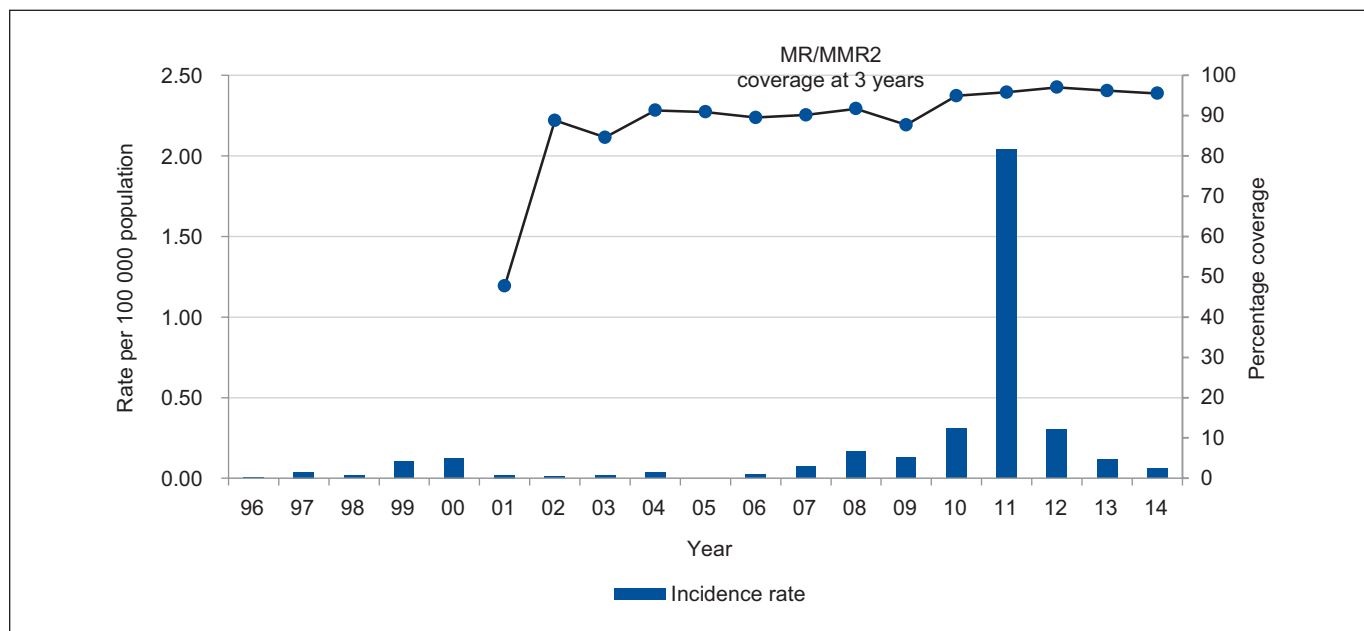


Figure 3: Incidence of rubella cases (1996–2014) and MR/MMR2 vaccination coverage (2001–2014)

MMR2: second measles–mumps–rubella vaccination (from 2011 to present); MR: measles–rubella vaccination (2001–2011).

Table 3: Rubella outbreak situation 2011 and CRS cases in 2012

District	Location	Number of rubella cases 2011	Number of CRS cases 2012
Gampaha	Factory 1	41	2
	Factory 2	31	
Galle	Military camp	12	2
Colombo	Hotel 1	14	2
Moneragala	Military camp	126	—
Polonnaruwa	Military camp	5	—
Badulla	Military camp	97	—
Anuradhapura	Military camp 1	22	—
	Military camp 2	25	—
Badulla	Military camp	37	—
Nuwara Eliya	—	—	2 ^a
Kurunegala	—	—	2 ^a
Ratnapura	—	—	1 ^a
Kalutara	—	—	1 ^a

^a Military personnel were from all over the country. CRS cases in districts that differed from those of military camps were probably due to transmission of rubella to susceptible females through military personnel who were asymptomatic had only mild infections.

to achieving zero endogenous transmission of rubella by 2020. National immunization coverage of RCVs (MR/MMR) at the age of 3 years has continued to be above 95% from 2010 to 2014, as reported through United Nations Children's Fund (UNICEF)–WHO joint reports (author permitted access to national data).

Despite all this, the authors understand the challenges ahead for completely eliminating CRS. Identification of population-level immunity by serosurveillance and population-susceptibility profiles is essential to ensure success. Community transmission of rubella disease is expected to be at a low level, owing to high coverage of rubella vaccination preventing sustained community transmission, through herd protection. But potential transmission in special situations, such as gatherings of adult males, is identified as a possible factor favouring transmission. Further, importation of rubella virus by international travellers is possible. However, establishment of transmission in the community is not likely to occur, owing to high rubella immunity among females and children aged up to 15 years.

Sri Lanka serves as a good example of how different combined strategies work to provide one path for success. Such different vaccine-implementation strategies pave the way for success in filling the gaps in population immunity, while a strengthened surveillance system detects cases early, using case-based investigations.

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Towards elimination of parent-to-child transmission of syphilis in India: a rapid situation review to inform national strategy

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ABSTRACT

In February 2015, India's National AIDS Control Organisation, Ministry of Health and Family Welfare, launched a national strategy towards elimination of parent-to-child transmission (E-PTCT) of syphilis, with a goal to reduce the incidence of congenital syphilis to 0.3 cases per 1000 live births by 2017. As part of the development of the national strategy, a rapid situation analysis was undertaken to ascertain the current practices, challenges and barriers for E-PTCT of syphilis in India. The analysis was conducted during February and March 2014 in five states selected from five different regions of India. Key informant interviews were conducted with key stakeholders at facility, state and district level. Content analysis was used to identify the themes. Key barriers identified for E-PTCT of syphilis were: low priority for antenatal syphilis testing among providers, limited access to testing, untrained human resources, shortage of test kits and benzathine penicillin, nonadherence to the national protocol for syphilis testing, and poor recording and reporting of antenatal syphilis data. The analysis also identified opportunities for functional integration of E-PTCT within existing maternal and child health programmes. Health-care providers and programme managers expressed a need for training in the programme for E-PTCT of syphilis. The situation analysis identified that, for successful implementation of E-PTCT of syphilis, it is essential that state and district programme managers adopt this initiative; coordinate the programme; plan for an adequate budget in their programme implementation plan; ensure an uninterrupted supply of standardized diagnostics kits and drugs at all levels of health care; and adhere to E-PTCT guidelines when implementing the programme.

Key words: challenge, congenital syphilis, India, pregnant women, syphilis elimination

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BACKGROUND

Globally, about 1.5 million pregnant women are infected with probable active syphilis each year, and approximately half of infected pregnant women who are untreated will experience a wide spectrum of adverse outcomes, such as early fetal loss and stillbirth, neonatal death, low-birth-weight infants, and infants with clinical evidence of infection (congenital syphilis).¹ In the World Health Organization South-East Asia Region, nearly 600 000 pregnant women are estimated to be newly infected with syphilis each year;² in 2012 there were 103 960 cases of maternal syphilis in India, with an estimated 16 324 cases of congenital syphilis.³

Congenital syphilis is a serious but preventable disease, which can be eliminated through effective screening of pregnant women for syphilis and treatment of those infected; thus, a global initiative to eliminate mother-to-child transmission of syphilis was launched in 2007.⁴ Subsequently a strategy was launched in 2009 for the elimination of congenital syphilis in the South-East Asia Region in 2011–2015.^{5,6} After wide discussions with the relevant stakeholders, and national and international experts, the National AIDS Control Organisation (NACO) in India also developed and launched a national strategy for elimination of parent-to-child transmission (E-PTCT) of syphilis in February 2015.³

The NACO E-PTCT of syphilis has the following targets: early screening of at least 95% of pregnant women for syphilis during their routine antenatal check-up, adequate treatment of at least 95% of seroreactive pregnant women, and treatment of 100% of neonates and partners exposed to syphilis. The goal of the initiative is to reduce the incidence of congenital syphilis in India from 0.6 per 1000 live births (current estimate) to 0.3 cases per 1000 live births by 2017.³

While developing the national strategy for E-PTCT of syphilis, it was clear that there was a scarcity of literature and studies in India on the contextual barriers and the factors that enable success in achieving such ambitious programme targets across diverse geographical locations. To inform the national strategy, a rapid situation review was undertaken to identify opportunities available and functional barriers to implementing E-PTCT of syphilis. The aim of this study was to highlight practices, challenges and opportunities around testing, treatment and reporting of syphilis-reactive pregnant woman, and their partners and exposed babies.

APPROACH

The rapid situation analysis was conducted by the sexually transmitted infections (STI) division of NACO during February and March 2014 in five states (Madhya Pradesh, Maharashtra, Sikkim, Tamil Nadu and Uttar Pradesh), which were purposively selected as representative of north, central, eastern, south and west zones of the country. The national health mission (NHM) categorized the states into four different regions based on health indicators and geographical area (see Table 1).⁷

One high-priority district (category A or B) for HIV intervention was purposively selected from each of Maharashtra, Tamil Nadu and Madhya Pradesh. In Uttar Pradesh, one category C, or lower-priority, district was selected, and in Sikkim two category C districts were selected for the study.⁸

In total, four medical colleges, five district hospitals, five community health centres, four primary health centres, three subcentres and two private health facilities were visited in the

selected districts. All the facilities visited were delivery points for pregnant women. Delivery points are health facilities that have a high demand for services and performance above a certain benchmark, with the objective of providing comprehensive reproductive, maternal, newborn, child and adolescent health services (RMNCH+A).⁷

Ten key officials involved in planning and implementation of the STI programme at state and district level from the HIV and maternal health programmes were interviewed using a structured interview guide. Information was gathered on current practices and challenges in syphilis screening, and testing and treatment options for antenatal clients. The information enabled the identification of opportunities available and possible challenges to expanding syphilis screening and testing through functional integration of syphilis screening within existing programmes: RMNCH+A, the STI/RTI [reproductive tract infection] Control and Prevention Programme, and Prevention of Parent-to-Child Transmission (PPTCT) of HIV using Multi Drug Anti-retroviral Regimen in India.

At the facility level, information was gathered from 30 members (including doctors, nurses, designated STI/RTI clinic [DSRC] and PPTCT counsellors, and laboratory technicians) using a semi-structured interview guide. Interviews were led by an STI consultant and facilitated by programme officers and experts from the STI division of NACO. Information was gathered regarding routine services offered in antenatal care (ANC) and functional links with PPTCT centres and DSRCs, and challenges around diagnosis, treatment and reporting of maternal syphilis and congenital syphilis. Additional information on capacity-building, supervision, supply-chain management, and funding and resource allocation for ANC, PPTCT and DSRC/STI services was also collected.

For the analysis, the data from the semi-structured interviews and in-depth interviews with key stakeholder were categorized into two main themes, challenges and opportunities, using content analysis. All the responses were recategorized into domains such as accessibility to syphilis testing among pregnant women, recording and reporting practices, monitoring and evaluation systems, human resources available, training needs, supply of syphilis test kits and source of funding, point-of-care

Table 1: States and districts selected from five different geographical zones of India

State	Region of India	District selected (HIV district category ⁸)	National Health Mission: state categorization ⁷
Madhya Pradesh	Central	Bhopal (B)	High-focus large state (weak public health indicators, high unmet needs for public health infrastructure and large population size)
Maharashtra	West	Thane (A)	Non-high-focus large state (comparatively better public health indicators and large population size)
Tamil Nadu	South	Kancheepuram (B)	Non-high-focus large state
Sikkim	East	East and south districts (C)	High-focus small state (weak public health indicators, high unmet needs for public health infrastructure and small population size)
Uttar Pradesh	North	Sitapur (C)	High-focus large state

testing for syphilis, drugs for management of syphilis-reactive pregnant women and their partners and newborn infants, perspectives of programme managers, and perspectives of private practitioners.

OBSERVATIONS

Key challenges to E-PTCT for syphilis

The study revealed the key challenges to E-PTCT of syphilis, as summarized next.

Accessibility to syphilis testing among pregnant women

Participants reported different practices among states and among the levels at which antenatal care was provided. In medical colleges and district hospitals, screening for syphilis (either rapid plasma reagin [RPR] or venereal disease research laboratory [VDRL] test) was offered to all ANC clients in all the five states except in the district hospital in Sitapur in Uttar Pradesh, where the rapid syphilis test (treponemal-based) was used. The rapid syphilis test was also used at primary health centres and community health centres in Maharashtra, Tamil Nadu and Uttar Pradesh. In Madhya Pradesh, the syphilis test was not offered to ANC clients attending facilities below district level. In Madhya Pradesh, gynaecologists prescribed the syphilis test to selected ANC clients, based on certain eligibility criteria, such as history of a previous caesarean section or blood transfusion, or a complex obstetric history.

Participants reported that sera found to be reactive qualitatively or by the rapid point-of-care treponemal test were not subjected to a quantitative test (titres). The reasons given by participants were: overburdened laboratory technicians, lack of laboratory staff (unfilled approved positions), shortage of test kits, and lack of clear allocation of responsibilities.

Participants reported that the observed syphilis reactivity among pregnant women was very low and this was reported in official data at the district level. However, there were no systems of quality assurance and quality control for syphilis testing at any level of health-care facility. Further, it was also observed that there was a wide variation in the type of test kits used for syphilis screening, (ranging from RPR to modified VDRL, to point-of-care immunochromatographic tests).

Recording and reporting practices

Record keeping and reporting of syphilis data were found to be poor. Participants reported inconsistent practices in recording syphilis screening and test results on ANC cards and in reproductive and child health registers. Information on the number of ANC clients screened and found to be reactive for syphilis was routinely reported by all DSRCs supported by NACO through its Strategic Information Management System, but this was carried out in only a limited number of facilities. However, the health facilities under the NHM-reported syphilis

screening data in the Health Management Information System (HMIS) and the Mother and Child Health Tracking System (MCTS). There was no reporting of congenital syphilis cases in any of the facilities.

Monitoring and evaluation systems

According to the participants, ANC syphilis testing and treatment was poorly monitored by state AIDS prevention and control societies, and NHM. This was because of the low priority of the STI programme in the NHM programme, and lack of national guidelines on E-PTCT. The district hospital and medical college facilities were monitored by an STI focal person in state AIDS prevention and control societies. The subdistrict-level facilities were monitored by NHM functionaries. The state programme officers felt that E-PTCT of syphilis might be functionally integrated into NHM across all states and union territories, to enable it to reach a large number of ANC facilities for syphilis screening.

Human resources

Participants reported a significant number of vacancies for approved laboratory-technician posts in the subdistrict-level health facilities across the states. As a consequence, there was poor adherence to standard operating procedures. Doctors working at primary health centres and community health centres reported that they do not routinely manage cases of syphilis-reactive mothers and babies at their facilities. Most of them stated that they preferred to refer the syphilis-reactive cases to medical college hospitals for further management.

Training needs

Health-care providers from all levels of facilities (that is, from medical colleges to subcentres) expressed the need for training in the interventions recommended in the programme for managing maternal and congenital syphilis. Staff generally lacked a clear understanding of national guidelines. The state programme officers suggested that there might be an opportunity to train and use community health workers, such as accredited social health activists. In Uttar Pradesh, the programme managers also expressed a need to train doctors practising other forms of medicine, such as homoeopathy, unani or ayurveda, who were providing services to ANC facilities.

Supply of syphilis test kits and source of funding

There had been a shortage in supply of RPR kits at all DSRCs for the past year. The medical college hospitals procured syphilis test kits from hospital funds. In Maharashtra, Uttar Pradesh and Tamil Nadu, state governments procured rapid-test kits from Janani Shishu Suraksha Karyarama (JSSK) funds, Rogi Kalyan Samiti funds of NHM/State Health Mission, or the state health budget. It was also observed that test kits were stored inadequately, and that the first-expired, first-out

principle was not being followed for kit use. Participants also noted poor adherence to protocols for disposal of biological waste in most of the subdistrict-level facilities.

Point-of-care test for syphilis

States were willing to roll out syphilis screening using the point-of-care test, provided that the test kit could use finger-prick whole blood as the sample. The auxiliary nurse midwives in Maharashtra, Tamil Nadu and Madhya Pradesh were willing to use the point-of-care test for syphilis at the subcentre level, provided they were trained on how to do the test. The programme managers were of the opinion that the point-of-care test would not only ensure rapid scale-up of screening for syphilis among pregnant women, but also enable screening of pregnant women who arrive in the labour rooms without previous test reports for syphilis. The providers and managers expressed the concerns that large numbers of false-positive cases could be reported by use of the point-of-care test, and that storage of the point-of-care test kits may be a challenge in the summer season.

Drugs used in the management of syphilis-reactive pregnant women, and their partners and neonates

Benzathine penicillin is the drug of choice for managing maternal syphilis. Because of infrequent syphilis screening in the lower-level facilities and very low prevalence of maternal syphilis, injection of benzathine penicillin was not available in facilities below district level in Madhya Pradesh, Tamil Nadu and Uttar Pradesh. However, in Maharashtra, the drug was available in all levels of facilities. Azithromycin and erythromycin were available at all levels of facilities in the five states included in the study; these antibiotics are indicated only when the mother has a history of anaphylactic reaction to penicillin, and their use must be followed by adequate treatment of the neonate. Below district level, health-care providers were not very confident with using injections of benzathine penicillin because of fear of anaphylaxis. Overall awareness and alertness for early detection and management of maternal and congenital syphilis was observed to be low in all states in the study.

Perspectives of programme managers

Programme managers demonstrated a lack of awareness regarding the burden of maternal syphilis and the cost-effectiveness of intervention. They reported that syphilis is given a low priority throughout the ANC setting and they highlighted the absence of any policy documentation to guide them. Irrespective of the health-care setting, logistic planning for syphilis in pregnancy was lacking in all facilities. It was clear that planning was hindered by complexities such as dual funding from NACO and NHM for syphilis testing in different levels of facilities, and lack of coordination between state AIDS prevention and control societies and NHM. As a consequence, programmes were poorly monitored, and reported data were not utilized to improve services.

Perspectives of private practitioners

Private practitioners reported that they were not regularly screening pregnant women for syphilis, as this was not seen as an essential test in ANC. Most were of the opinion that syphilis is no longer an important disease to be included in ANC screening programmes. They were not seeing many cases of syphilis either clinically or serologically. Private practitioners were not using injection of benzathine penicillin to treat any of the illnesses and had expressed fear of managing anaphylactic reactions.

Key opportunities for E-PTCT of syphilis

The key opportunities identified are summarized in Table 2.

LESSONS LEARNT AND THEIR APPLICATION TO NATIONAL STRATEGY

The rapid situation analysis identified many missed opportunities and functional barriers to implementing E-PTCT of syphilis. The key barriers identified prior to the launch of the national strategy for E-PTCT for syphilis were: inadequate testing kits and drugs at all levels of health care, significant numbers of vacancies for laboratory-technician posts, lack of trained laboratory technicians, inconsistency in the testing protocol, lack of awareness among providers, use of nonstandardized test kits, fear of using benzathine penicillin among providers, gaps in recording and reporting of syphilis testing and results, and not including syphilis testing as an essential test in ANC.⁹

The main opportunity to implement E-PTCT of syphilis is to provide services through an existing functional maternal health programme, such as JSSK,¹⁰ and also the recent inclusion of syphilis in the essential ANC package of services. Functional cooperation between HIV/STI and RMNCH+A programmes, along with provision of point-of-care testing at the subcentre level and task shifting, will enable universal syphilis screening in India, including an estimated 29 million pregnant women.¹¹ The importance of implementing a combined E-PTCT programme as an integrated initiative to eliminate both HIV and syphilis, as highlighted by The Asia-Pacific Prevention of Parent-to-Child Transmission Task Force for HIV and syphilis, in a regional strategy released in 2011,² will enable the programme to achieve the dual elimination goal.

This study highlighted that it is essential to empower health-care providers in diagnosis of maternal and congenital syphilis and use of benzathine penicillin for treatment.^{12,13} Adequate budgetary provision in state programme implementation plans will ensure adequate allocation of resources for procuring test kits and drugs such as injectable benzathine penicillin, azithromycin and erythromycin, to treat syphilis in all levels of facilities. No proven alternative to penicillin exists for the treatment of syphilis during pregnancy. Use of azithromycin and erythromycin should be restricted to pregnant women who have a history of severe penicillin allergy (for example,

Table 2: Key opportunities identified to enable E-PTCT of syphilis in India

Domain	Opportunities for improvement
ANC syphilis testing	<ul style="list-style-type: none"> Consider syphilis testing as part of the essential ANC package at all levels Link syphilis testing with client's first ANC visit Link syphilis programme with PPTCT programme
Recording and reporting	<ul style="list-style-type: none"> Record syphilis test results and treatment in ANC cards Include E-PTCT of syphilis core indicators in HMIS and MCTS Train staff in recording and correct reporting of E-PTCT indicators by health facilities at all levels
Human resources	<ul style="list-style-type: none"> Recruit laboratory technicians to fill vacant approved positions Involve existing paramedical staff in syphilis testing by introducing POC testing Adhere to existing standard operational procedures for testing and disposal of biological waste
Training and capacity-building	<ul style="list-style-type: none"> Train all groups of maternal and child health staff on E-PTCT for syphilis Train laboratory technicians on standard operating procedures Train paramedical staff on use and storage of POC test kits Train staff on external quality-assurance services at all levels
Diagnostic and drug logistics	<ul style="list-style-type: none"> Procure drugs and diagnostics through Janani Shishu Suraksha Karyakram funds Implement external quality-assurance services at all levels Display standard operational procedures for quality testing at all facilities Develop cooperation between NACO and NHM for procuring diagnostic kits and generic medicines
Programme managers	<ul style="list-style-type: none"> Develop a policy document to enable programme managers to understand their roles and responsibilities Develop dashboard indicators that state and district programme managers can use for monitoring Facilitate joint planning by state AIDS prevention and control societies and NHM to enable adequate procurement and supply of test kits and drugs Enable monthly review and monitoring of commodities at state and district levels

ANC: antenatal care; E-PTCT: elimination of parent-to-child transmission; HMIS: Health Management Information System; MCTS: Mother and Child Health Tracking System; NACO: National AIDS Control Organisation; NHM: National Health Mission; PPTCT: prevention of parent-to-child transmission (of syphilis).

anaphylaxis). All infants of pregnant women treated with a non-penicillin regimen should be treated at birth as if the mother was inadequately treated.³

However, in the light of very low prevalence of maternal syphilis, the district health authorities or the head of the facility should be granted permission to procure the drugs, if required, on a case-by-case basis, to facilitate the timely availability of drugs to treat the disease. Uninterrupted supply and maintenance systems for diagnostic kits and drugs for syphilis treatment are key elements for smooth implementation of an E-PTCT programme. These will facilitate universal syphilis screening in ANC and enable prompt treatment of women testing positive; these are the basic interventions that have been proven to be cost-effective, even in settings where there is a low prevalence of syphilis.¹⁴ Women found to be syphilis reactive in subcentre facilities should be referred to the nearest primary health centre/community health centre/district health

centre for treatment on the same day, and other facilities should also treat syphilis-reactive pregnant women on the same day as diagnosis.³

There should be training and capacity-building for those staff involved in providing ANC and those who are responsible for reporting cases. National-level orientation is required for state-level key stakeholders, to ensure that there is standardized management of cases of maternal and newborn syphilis, and regular reporting. The training should be integrated into maternal and child health training programmes. A special recruitment drive to fill job vacancies for all levels of staff will give a strong impetus to effective implementation of the programme for E-PTCT of syphilis.

According to the programme data available from NACO and HMIS, around 5 million pregnant women were screened for syphilis in 2012–2013.³ Of the pregnant women found

to be infected, only 35.8% were treated for syphilis.¹⁵ The low levels of screening for syphilis in ANC could be due to lack of a policy for syphilis testing, and the fact that syphilis testing is not essential in ANC services.¹⁶ The new policy that includes syphilis testing as part of the essential ANC package is an opportunity for ANC to significantly increase testing for syphilis.

In this study, it was found that there was no standard format for recording of service-delivery data. There is a need to set up a surveillance system for maternal and congenital syphilis. Once a robust surveillance system is established, as specified in the implementation guidelines, the monitoring of core indicators will play a crucial role in the steps taken towards validation of E-PTCT of syphilis.¹⁷

Study limitations

The study findings cannot be generalized to the entire country. Although an attempt was made to represent five different regions, each state/union territory has a unique context in India. Therefore, it is possible that there are more state-specific challenges and opportunities that were not identified in this study because of the limited number of facilities visited. The findings of the study were helpful in refining the national strategy for E-PTCT of syphilis that was launched in February 2015.

CONCLUSION

This study facilitated the opportunity for the RMNCH+A programme to revise the ANC services and to include syphilis and HIV screening in the essential package of services for ANCs. The successful implementation of E-PTCT for syphilis requires state and district programme managers from AIDS control societies and health missions to coordinate and plan a definitive road map for adequate resource allocation for procurement of sufficient quantities of test kits (including point-of-care tests) and benzathine penicillin for screening and treating syphilis in all ANC facilities. The maternal and child health staff at all levels should be adequately trained for intervention and reporting of syphilis cases. HMIS should include core indicators to monitor E-PTCT of syphilis. There should be ongoing mentoring and supportive supervision of staff, and monitoring of programme implementation. The private providers are also encouraged to screen, treat and report maternal syphilis.

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Landscaping capacity-building initiatives in epidemiology in India: bridging the demand-supply gap

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ABSTRACT

India, the second most populous country in the world, has 17% of the world's population but its total share of global disease burden is 21%. With epidemiological transition, the challenge of the public health system is to deal with a high burden of noncommunicable diseases, while still continuing the battle against communicable diseases. To combat this progression, public health capacity-building initiatives for the health workforce are necessary to develop essential skills in epidemiology and competencies in other related fields of public health. This study is an effort to systematically explore the training programmes in epidemiology in India and to understand the demand–supply dynamics of epidemiologists in the country. A systematic, predefined approach, with three parallel strategies, was used to collect and assemble the data regarding epidemiology training in India and assess the demand–supply of epidemiologists in the country. The programmes offering training in epidemiology included degree and diploma courses offered by departments of preventive and social medicine/community medicine in medical colleges and 19 long-term academic programmes in epidemiology, with an estimated annual output of 1172 per year. The demand analysis for epidemiologists estimated that there is need for at least 3289 epidemiologists to cater for the demand of various institutions in the country. There is a wide gap in demand–supply of epidemiologists in the country and an urgent need for further strengthening of epidemiology training in India. More capacity-building and training initiatives in epidemiology are therefore urgently required to promote research and address the public health challenges confronting the country.

Key words: capacity-building, demand and supply, epidemiologists, epidemiology, India

BACKGROUND

India, the second most populous country in the world, has 17% of the world's population but its total share of global disease burden is 21%.¹ A large portion of this disproportionately high burden is contributed by preventable communicable diseases.² The dynamics of pathogens, further compounded by factors that favour emergence and fast spread of infectious diseases, demand epidemiological competencies in compilation, assessment and interpretation of data (from various sources of health, meteorological and related areas), making use of the information to initiate appropriate and timely public health measures.³ With epidemiological transition, the challenge of the public health system is to deal with a high burden of noncommunicable diseases, while still continuing the battle against communicable diseases. Challenges in disease control

are formidable and range from influencing the factors that drive disease emergence, to making surveillance systems fit for purpose and improving control interventions.⁴ Inequalities in access to health care by socioeconomic status, geography and sex, and the struggle of the health facilities to cope with a large population, make priority-setting crucial. Overcoming all these challenges requires a workforce equipped with essential skills in epidemiology and competencies in other related fields of public health. In recent times, the role of epidemiologists has gained prominence, with introduction of the Integrated Disease Surveillance Project (IDSP), which established the position of epidemiologists at district level. Epidemiologists are also needed at medical colleges, international organizations, bilateral organizations, public health projects, research and training institutions, national health programmes and nongovernmental organizations.

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Epidemiology provides a sound and rational foundation for public health professionals to develop public policies and make meaningful decisions. It also provides a rational basis for allocating resources. Taking into account the multiple applications of epidemiological skills in public health, there exists a need to develop epidemiological competencies in health professionals, to help them identify problems, formulate solutions and identify application of such information for public health action.

The major challenge in the World Health Organization (WHO) South-East Asia Region is the inadequate number of professionals and other non-medical health staff who have been trained in epidemiology.⁵ In India, although there have been capacity-building measures for training in epidemiology, the numbers are still insufficient, considering the continuously growing need for skilled epidemiologists in the country. Although this concern has been voiced at several forums, little attempt has been made to analyse the current status of epidemiology training and capacity-building initiatives in the country.

This paper reviews the capacity-building initiatives in epidemiology in India, to aid understanding of the demand–supply gap of epidemiologists and to give future directions for initiating need-based training.

METHODOLOGY

Data regarding capacity-building initiatives in epidemiology were collected using three strategies. A systematic, predefined approach was used to obtain this information. Each step was conducted in a parallel manner, and the information was entered into an Excel spreadsheet. The first search strategy involved using the information available on the internet. The internet search was conducted using the Google search engine. The first step in this strategy involved identifying a set of key words encompassing various domains related to epidemiology courses. The key words included “epidemiology”, “research methods”, “field epidemiology training programme” and “epidemiology training”. The search was limited to courses offered in India and to collaborations between Indian and foreign institutions, if any. The websites of premier institutions involved in teaching and training of public health, professional organizations and universities were also visited. Detailed information about the courses offered was collected from the respective institutions through their websites and/or by telephone communication.

The second strategy involved a detailed literature review of the epidemiology courses. Indexed and non-indexed journals in the field were identified and searched for notifications and invitation of nominations for educational courses. Key institutes involved in research in epidemiology were identified from the author affiliations. Additional information about short-term training programmes in epidemiology was obtained from this strategy.

The third strategy involved contacting experts in the field of epidemiology in India. This was done by email and/or telephone. They were requested to share information about the courses offered in their institutes and also to suggest the names of other institutes offering courses in the identified fields. This strategy was useful for gathering information on course curriculum, intake capacity of institutions and eligibility criteria.

The search was directed at obtaining data on the following parameters: name and location of the institute offering the course; theme and course duration; course structure; eligibility criteria; and the capacity of training. These parameters were incorporated in a matrix. Data were entered in an Excel spreadsheet with information about the institutions, under the headings (i) institution name and address; (ii) name of course; (iii) duration of course; (iv) intake capacity; (v) year of start of course; (vi) eligibility criteria; and (vi) other comments. After obtaining the list of institutions and their contact details, detailed information about the epidemiology programme, covering the number of sanctioned and filled places, the curriculum, fees, teaching and evaluation systems, was sought from the department/school offering the programme, via email and through telephone follow-up. A structured questionnaire was designed to collect detailed information from the various institutes identified as providing epidemiology courses in India. The questions included information on the type of institute, whether it was government or private, and the year of inception of the course. When information was gathered about a course, the course name was entered in the matrix, and available information about the course and institution was entered through that data source. After that, an attempt was made to verify the data and collect missing data by searching for the email address/telephone number of the institution and contacting them directly.

Any other salient features of relevance to the courses were also incorporated subjectively into this matrix.

To undertake the demand–supply analysis of epidemiologists in the country, first the supply was calculated, based on the output from long-term training programmes in epidemiology. The cumulative output from all training programmes in epidemiology was calculated, to estimate the annual supply of epidemiologists in the country. The demand for epidemiologists was computed by gathering information on the requirement for epidemiologists in epidemiological practice, research and education. For this purpose, an internet search was done to note the requirement and vacancies for epidemiologists in various institutions. The website of the Medical Council of India was browsed to get information on the requirement for epidemiologists in medical colleges. Similarly, the websites of the Ministry of Health and Family Welfare, Indian Council of Medical Research (ICMR) and IDSP were visited, to gather information on the demand for epidemiologists in their offices. Based on the information on long-term training programmes in epidemiology, the demand for faculty in these institutions was calculated. In parallel, information on the demand for epidemiologists was also gathered by contacting experts in the field of epidemiology, to identify programmes/projects where epidemiologists are required.

RESULTS

Epidemiology training In India

Different epidemiology training programmes in India were classified under four broad categories:

1. long-term academic programmes
2. field epidemiology training programmes
3. programmes offered as part of medical and public health education
4. short-term training programmes of less than 6 months' duration.

Long-term academic programmes in epidemiology

These courses include PhD (Doctor of Philosophy), DNB (Diploma of National Board), MSc (Master of Science), MPhil (Master of Philosophy) and MPH (Master of Public Health), as well as diploma programmes specializing in epidemiology, as summarized in Table 1. Most of the programmes have an eligibility criterion of a graduate degree in medicine or allied sciences, and their duration ranges from 1 to 5 years. Some programmes are only for medical professionals, while others admit students from allied fields. All programmes have classroom teaching as the main teaching method and most of them require research work to be done, leading to the award of a degree/diploma.

Field epidemiology training programmes in India

The training programmes in field epidemiology in India have a long history. A 3-month field epidemiology training programme was started during 1963–64.⁶ Most short-term field epidemiology training programmes (FETPs) are offered by the National Centre for Disease Control (NCDC), New Delhi. (see Table 2).⁷ In 2001, the National Institute of Epidemiology, Chennai started the 2-year Master of Applied Epidemiology (MAE) programme. This programme was modelled on the Epidemic Intelligence Services (EIS) programme of the United States (US) Centers for Disease Control and Prevention,⁸ and the MAE programme of the Australian National University.⁹ In 2006, NCDC started the 2-year MPH (Field Epidemiology) course. The India EIS was launched in October 2012, and is modelled on the US EIS programme and adapted to Indian conditions. MPH (Field Epidemiology) and MAE are the members of the TEPHINET Training Programmes in Epidemiology and Public Health Interventions Network.¹⁰

Other capacity-building initiatives include the establishment of networks and alumni associations for epidemiologists. These networks play an invaluable role in sharing of experiences and lessons, advocacy and improving quality of training. Alumni networks are being maintained by most of the institutions offering epidemiology programmes.

Epidemiology training as part of medical and public health education

Epidemiology training as part of medical education

Table 3 shows the list of medical programmes that include epidemiology as a part of their curriculum, with details on the number of institutions and annual output of graduates.^{11–13}

As a part of undergraduate training, medical graduates are taught the basic principles of epidemiology and biostatistics during the third year of the course. Epidemiology training is an important part of Doctor of Medicine (MD) programmes in community medicine/preventive and social medicine, community health administration and hospital administration, and the skills expected after the completion of this course include application of the principles of epidemiology and biostatistics for public health. During this 3-year training programme, a student is expected to complete at least one research project as a part of their dissertation, which is mandatory for the award of this degree. Other training programmes in these disciplines that incorporate training in epidemiology include the PhD (Community Medicine) offered by the All India Institute of Medical Sciences.

Epidemiology training as part of public health education

Traditionally, public health education in India was offered through medical colleges and was open for medical graduates only. However, with the growing recognition of public health as a multidisciplinary subject, there is a conscious shift in public health education in India, with institutions other than medical schools initiating public health education programmes for medical and non-medical graduates. Besides the medical schools, epidemiology is currently a part of MPH, postgraduate programmes in health management, hospital management/administration, occupational and environmental health programmes and veterinary science courses. The annual intake of these programmes is shown in Table 4.^{14–17}

Apart from the four institutes that offer dedicated programmes in epidemiology (see Table 1), the rest of the MPH programmes offer a compulsory module on epidemiology as part of their training in public health. Epidemiology training in these courses includes basic epidemiology with biostatistics, along with practical application of these skills by conducting project work.

Short-term training programmes in epidemiology

NCDC, formerly the National Institute of Communicable Diseases, New Delhi; the ICMR group of institutes; Public Health Foundation of India; National Institute of Epidemiology (NIE) Chennai; Christian Medical College, Vellore; Post Graduate Institute of Medical Sciences and Research, Chandigarh; National Institute of Health and Family Welfare, New Delhi; Mahatma Gandhi Institute of Medical Sciences, Sevagram; and All India Institute of Hygiene and Public Health, Kolkata are some premier institutes offering short-term training programmes in epidemiology on a periodic basis.

Table 1: Long-term academic courses in epidemiology in India

Institute	Course	Duration (years)	Type of course	Enrolment capacity	Eligibility criteria
Doctorate degree (PhD)					
National Institute of Mental Health and Neurological Sciences, Bangalore	PhD (Epidemiology)	2–5	PhD	—	MD PSM/Community Medicine/ MSc
National Institute of Epidemiology (ICMR), Chennai	PhD (Biostatistics and Epidemiology)	2–5	PhD	—	MD/MSc
Tata Memorial Hospital, Mumbai	PhD (Epidemiology)	5	PhD	1 per year	MBBS/Masters in Life Sciences
The Tamil Nadu Dr MGR University, Chennai	PhD (Epidemiology)	3–5	PhD	3 so far	Masters degree in Epidemiology
Achutha Menon Centre for Health Sciences Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala	PhD (Epidemiology)	3–5	PhD		MBBS with marks of >60%
Diplomate of National Board (DNB)					
National Board of Examinations	DNB (Field Epidemiology)	—	DNB	—	MPH (Field Epidemiology) from NCDC, Delhi; 2 years' field experience
National Board of Examinations	DNB (Epidemiology)	—	DNB	—	MBBS, Previous training and experience in epidemiology
Masters courses					
Master of Science (Epidemiology)					
The Tamil Nadu Dr MGR University	MSc Epidemiology	2	MSc	4	Graduate in health sciences, any medical related MSc, MA (Social Work); 3 years' experience
Christian Medical College, Vellore	MSc Epidemiology	2	MSc	8	Graduate in health sciences, any medicine-related MSc, MA (Social Work)
Master of Public Health					
All India Institute of Hygiene and Public Health, Kolkata	MPH Epidemiology	2	MPH	20	Medical graduates
Department of Public Health, Manipal University, Manipal, Karnataka	MPH Epidemiology	2	MPH	18	Bachelor's degree in medicine, dentistry, nursing, allied health, life science from a recognized university with a minimum of 60% marks in aggregate
Tata Institute of Social Sciences, Mumbai	MPH Social Epidemiology	2	MPH	20	Medical graduates or a master's degree in any discipline, or non-medical graduates with minimum 2 years' experience in the health sector after graduation
National Institute of Epidemiology, Chennai	MPH (Epidemiology and Health Systems)	2 (13 months at NIE, 11 months in field)	Masters	20	MBBS; working in public health, preferably in state or central government department/ medical institutions, age <45 years

Institute	Course	Duration (years)	Type of course	Enrolment capacity	Eligibility criteria
MPhil (Clinical Epidemiology)					
Clinical Epidemiology Research Training Centre, Medical College, Thiruvananthapuram	MPhil (Clinical Epidemiology)	2	Masters	8	MD/MS/MDS, age <45 years
Masters Course in Epidemiology and Clinical Research in Oncology					
Tata Memorial Hospital, Mumbai	Masters Course in Epidemiology and Clinical Research in Oncology	2	Masters	6	Postgraduate in life sciences/medical; age <40 years; 60% mark in postgraduate degree, last advertised in 2006, no notices thereafter
Postgraduate Diploma					
Public Health Foundation of India, Delhi	Postgraduate Diploma in Epidemiology (Distance Learning)	1	Postgraduate diploma	—	Graduate/postgraduate degree in medical and allied fields, with relevant experience in public health; candidates engaged in public health-related activities in central/state government/national programmes/health-related organizations/nongovernmental organizations
National Institute of Epidemiology, Chennai	Postgraduate Diploma in HIV Epidemiology	2	Postgraduate diploma	5	MBBS degree, current position in central/state government, preferably in HIV/AIDS control programme; minimum 2 years' experience in public health/HIV surveillance or programme-related activities; age 40 years or less; last advertised in 2012
Centre for Social Medicine, Loni	Postgraduate diploma in Epidemiology and Health Management	1	Postgraduate diploma	20	Undergraduate degree in medicine, health and allied sciences, or bachelor of any science subject from the UGC-recognized universities or possesses qualifications equivalent to an undergraduate degree
Diploma in Epidemiology (in-service programme under IDSP)	Public Health Foundation of India and National Health System Resource Centre	18 months	Postgraduate diploma	—	Epidemiologists working under IDSP

ICMR: Indian Council of Medical Research Master of Public Health; IDSP: Integrated Disease Surveillance Project; MA: Master of Arts; MBBS: Bachelor of Medicine, Bachelor of Surgery; MD: Doctor of Medicine; MS: Master of Surgery; MDS: Master of Science in Dentistry; MSc: Master of Science; MPhil: Master of Philosophy; NIE: National Institute of Epidemiology; PhD: Doctor of Philosophy; PSM: preventive and social medicine; UGC: University Grants Commission.

Table 2: Field epidemiology training programmes in India

Course name	Institution	Duration	Participants
Training programme on basic epidemiology, outbreak surveillance and response	NCDC, New Delhi	10 days	Paramedical staff
IDSP FETP	Various Institutes	2 weeks	District surveillance officers
Training on prevention and control of communicable diseases	NCDC, New Delhi	1 month	Paramedical staff from the WHO South-East Asia Region
Regional FETP	NCDC, New Delhi	3 month	Senior and mid-level health professionals from the WHO South-East Asia Region
Masters in Applied Epidemiology	NIE, Chennai	2 years	In-service health professionals
MPH (Field Epidemiology)	NCDC, New Delhi	2 years	MBBS, working in public health
EIS training programme	NCDC, New Delhi	2 years	MBBS and MD (Community Medicine) or MD (paraclinical) with 2 years' experience

EIS: India Epidemic Intelligence Service; FETP: field epidemiology training programme; IDSP: Integrated Disease Surveillance Project; MBBS: Bachelor of Medicine, Bachelor of Surgery; MD: Doctor of Medicine; MPH: Master of Public Health; NCDC: National Centre for Disease Control; NIE: National Institute of Epidemiology; WHO: World Health Organization.

Table 3: Medical training programmes including epidemiology as part of the curriculum¹¹⁻¹³

Course	Number of institutions	Annual intake capacity
MBBS	412	52 325
MD (Community Medicine/Preventive and Social Medicine)	229	802
Diploma in Public Health	39	90
Diploma in Community Medicine	6	11
MD (Hospital Administration)	8	31
MD (Community Health Administration)	1	10
Masters in Hospital Administration	2	24
Diploma (Health Administration)	1	6
Diploma (Hospital Administration),	1	6

MBBS: Bachelor of Medicine, Bachelor of Surgery; MD: Doctor of Medicine.

Table 4: Public health programmes offering epidemiology training, with annual intake capacity

Academic stream	Annual intake/year
Health management	2500
Hospital management and administration	2473
Masters in Public Health	623
Occupational and environmental health	460
Veterinary sciences	1500

The duration of these courses varies from 5 days to 6 months. Some short-term training programmes also incorporate training in specific statistical software packages. The Industrial Toxicology Research Centre, Lucknow, offers training in the subspecialty of environmental epidemiology, while the National Institute of Mental Health and Neurosciences, Bangalore, conducts training in neuropsychiatric epidemiology.

Other capacity-building measures

The role of professional organizations in capacity-building in epidemiology

Several professional organizations in the country, including the Indian Association of Preventive and Social Medicine, Indian Public Health Association, Indian Association of Epidemiologists, Indian Society of Medical Statisticians and Indian Association of Occupational Health, have played a

pivotal role in building the capacity of health professionals in epidemiology in India, and strive to continue in this endeavour. These organizations are conducting short-term training programmes and workshops on research methodology and epidemiology, through their national branch and state chapters.

The role of the World Health Organization

Realizing the limited capacity of the health staff in India in field epidemiology, WHO has been providing technical assistance to the national institutions involved in field epidemiology training. Two such courses supported by WHO are the 3-month FETP at NCDC and the 2-year MAE-FETP at NIE. Other than this, WHO supports various short-course training programmes.

In its roadmap to combat infectious diseases, the WHO Regional Office for South-East Asia developed a strategy that is consistent with the WHO *International Health Regulations (2005)*,¹⁸ which underlines the need for strengthening national capacity for surveillance, risk assessment, preparedness and response. Based on the roadmap and its strategy, WHO is working with Member States and other stakeholders to strengthen epidemiological capacity by promoting and strengthening the 2-year field epidemiology training programme and also short-term training (for 2, 4 and 13 weeks) in epidemiology, surveillance and prevention and control of communicable disease.¹⁹

To promote the application of epidemiology, both within WHO and in Member States, to programmes for disease prevention and control, an informal working group on epidemiology has been established in the WHO Regional Office for South-East Asia.²⁰ The mapping of epidemiology and related training capacity has also been undertaken as one of its activities to develop an overview of current capacity in epidemiology and related training programmes in the region.

The IndiaCLEN initiative

IndiaCLEN, one of the seven regional networks of the International Clinical Epidemiology Network (INCLIN), is a non-profit health-research network registered with the registrar of societies at Trivandrum, Kerala, since 1991. Beginning with a membership of 45, INCLIN has trained fellows in clinical epidemiology, health economics, biostatistics and health social sciences; IndiaCLEN currently has about 350 members across 135 medical institutions. To support the dissemination and application of clinical epidemiological principles in the education/research activities, IndiaCLEN has supported the establishment of clinical epidemiological units in 11 medical colleges. Apart from this, it has also supported the establishment of the Clinical Epidemiology Resource and Training Centre, Trivandrum, which offers an MPhil programme in clinical epidemiology.²¹

Institutional capacity-building initiatives

Another landmark in institutional capacity-building initiatives is the establishment of NIE at Chennai, with the broad

objectives of development of human resources in epidemiology and biostatistics and networking of the various institutes at the national level for epidemiological purposes. The institute has the distinction of being the WHO Collaborating Centre for Epidemiology of Leprosy and has been identified as a technical resource group for epidemiology of HIV by the National AIDS Control Organization. At present, it is one of the premier institutes for epidemiology training in India, with an area of field practice covering a well-characterized population of 500 000.²²

Demand–supply analysis

A supply analysis for epidemiology training was done through estimating the output of training programmes in epidemiology. The annual enrolment capacities of long-term academic programmes in epidemiology range from 1 to 20 per cohort. The potential training capacity per annum through the 19 long-term training programmes in epidemiology and three long-term FETPs is approximately 192 candidates per year. In addition, about 980 candidates complete their MD/Doctor of Public Health (DPH)/Doctor of Community Medicine (DCM) tenure every year, with a substantial part of their training time dedicated to epidemiology. As a result, approximately 1172 trained epidemiologists are added to the pool of epidemiologists each year. However, owing to more lucrative opportunities and the availability of jobs in other fields, eventually very few candidates with postgraduate degrees in preventive and social medicine/community medicine are available for jobs as epidemiologists.

There is dire need for epidemiologists in the country. As per the norms of the Medical Council of India, every medical college must have one epidemiologist under the Department of Preventive and Social Medicine/Community Medicine. With 412 medical colleges, this amounts to a demand for 412 epidemiologists by medical colleges alone.

Epidemiologists are also required as faculty for training programmes in this discipline. To serve the 19 long-term programmes in epidemiology and three long-term FETPs, 65 faculty members trained in epidemiology are required to serve these institutes, taking into account a faculty:student ratio of 1:1 for doctoral and 1:4 for masters' programmes. At least 135 additional faculty members are required to teach epidemiology in 135 institutes offering health management, hospital administration, public health and occupational health programmes, which include epidemiology as a part of their curricula.

Under the IDSP, the state surveillance team needs one epidemiologist at the state headquarters, amounting to 35 consultants and one epidemiologist for 676 districts. Besides this, trained epidemiologists are also needed for 26 permanent institutes under ICMR and national health programmes, as well as international organizations, bilateral organizations and NGOs in the health sector. The total estimated demand including all these sectors is for at least 3289 trained epidemiologists.

DISCUSSION

Capacity-building is much more than training and involves human-resource development and institutional and programme development conducive to the generation of appropriate responses to emerging needs.²³ Capacity-building in epidemiology was identified as an important and urgent issue during the South-East Asia Regional Conference on Epidemiology, New Delhi (March 2010), organized by WHO with several national and international partners.²⁴

Using a systematic approach, this study collected information about capacity-building initiatives in epidemiology and conducted a demand–supply situation assessment of epidemiologists in India. In the absence of an official database of epidemiologists in the country, the study used a search strategy employing tools like internet search, scanning information through peer-reviewed journals and contacting institutions and experts through email/telephone communication. Despite making efforts to collate data from as many sources as possible, there is a likelihood of missing out information that may not be captured by these data sources and this is one of the limitations of the study. Another limitation is that, in the demand–supply analysis of epidemiologists, the overall supply and demand of epidemiologists was calculated, irrespective of their training level or specialty. Epidemiologists trained outside the medical-college system may not be eligible for epidemiology teaching positions in government-run medical colleges. Similarly, those trained in one subspecialty of epidemiology may not be suitable for roles in other subspecialties. For a more accurate analysis, role-specific demand–supply analysis should be done, which is beyond the scope of this study. Another area that could be explored is an assessment of the manpower status of epidemiologists at various institutes. This would provide further information on the current scenario and identify the fields/institutes in which the demand–supply gap is largest.

In India, training in epidemiology is being delivered as part of many courses, as well as through dedicated programmes in epidemiology. The results of this study show that, despite the large population of the country, the enrolment capacity in most programmes still remains low, and in some cases even the available places are not always filled. In contrast to 19 long-term training programmes in epidemiology in India, the United States of America (USA), with one seventh of the population of India, has 402 masters' programmes in epidemiology. This is exclusive of 96 doctoral programmes in epidemiology and its subspecialties offered by various universities across USA.²⁵ With an increasing population in India, the need for trained epidemiologists is likely to increase. However, the limited numbers of trained professionals in epidemiology are going to be a restraint to catering for the increasing demand of training with time. Distance-learning courses have recently been launched and can probably cater for a larger audience with limited resources. In distance-learning mode, apart from the courses offered by Indian institutes, on which the present study focuses, international institutes can also contribute to capacity-building of professionals in India. This includes provision of long-term programmes and short courses, available either by enrolling in foreign universities or accessing open-source training materials like MOOCs (massive open online

courses). Though long-term academic programmes by foreign universities may not be affordable for all, because of high fees, the open-source platforms like MOOCs offer immense potential for capacity-building of epidemiologists, especially in subspecialties where there is lack of expertise in institutions across the country.

The results of this study show that courses are offered in the subspecialties of applied epidemiology, field epidemiology, social epidemiology and clinical epidemiology. The most frequently taught subspecialty is field epidemiology, with NCDC, Delhi, and NIE, Chennai, offering long-term courses in this subspecialty. Other specialties are taught only in selected institutes. At present, there are no courses focusing on environmental epidemiology, molecular epidemiology, seroepidemiology, occupational health epidemiology, and other subspecialties, thus providing abundant scope to expand the horizons of training in epidemiology by providing courses in these disciplines that are still unexplored.

The boundaries of epidemiology are shifting. The past decades ushered in unprecedented technological growth that led to innovations in communications and computation. Each of these elements has its place in epidemiology training and that can revolutionize and revitalize the teaching and practice of epidemiology. Training programmes in epidemiology can also make use of emerging newer technologies, such as for training in computation and the use of newer methods of communication for surveillance activities. Distance-learning courses can also be made interactive and user friendly, with the use of developments in telecommunication and various e-learning platforms.

Apart from increasing the output of programmes in terms of enrolment capacity and number of courses, which will require a lot of resources to cover and subsequently implement, concerted efforts should be directed towards improving the output of existing courses. As large numbers of skilled epidemiologists are a product of MD/diploma courses in community medicine/preventive and social medicine, revision of the curriculum for teaching epidemiology in these courses, to provide appropriate competencies to the students, would be one step closer towards achieving the larger goal and objectives.

Building institutional capacity is a crucial capacity-building measure, along with building human-resource capacity. Both are closely interrelated and complement each other. At present, few organizations are taking initiatives in this regard. However, this requires more attention, as capacity-building of the institutions need to be addressed at a long-term, strategic level and with panoramic thinking. This would also provide sustainability to the programmes and have a far-reaching impact.

Another issue that demands attention is the accreditation of courses in epidemiology, which can serve as step towards quality improvement in epidemiology training across the country. At present, although there are courses available for specialized training in epidemiology, they are imparted under different umbrellas and it is difficult to monitor their quality on a common platform. Courses offered in medical colleges are accredited by the Medical Council of India. Courses taught

outside the medical colleges are regulated by the university they are affiliated to, or the institutions where they are taught. At present, there is no separate body for accreditation of epidemiology or public health courses.²⁶ The possibility of establishing national accreditation standards can be explored in the near future, to further improve the expected outputs of training programmes offered.

In view of the large population of India, the supply of trained personnel in epidemiology is far from sufficient for the ever-growing demand for specialists in this field. This wide gap between supply and demand needs urgent attention. To fill this gap, there is a need to increase the number of training programmes, which in turn requires institutional strengthening and collaboration. For optimal use of expertise, there is a need to maintain an updated database of graduates in epidemiology and related training disciplines, and to establish functional networking of training programmes and alumni. Other initiatives that can improve the delivery of existing programmes are continuous quality-improvement procedures for curricula. Complementarities and integration of capacity-building initiatives themselves are of crucial importance. Without an adequate epidemiology workforce, public health cannot take off – and without public health programmes, disease prevention and health promotion will remain stunted. In short, planning for “human resources for health” without an overall strategy for epidemiology and epidemiologists is self-defeating.²⁷

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Innovative use of social media platform WhatsApp during influenza outbreak in Gujarat, India

Bhagyesh Shah, Shuchi Kaushik

Between November 2014 and April 2015, India experienced a severe outbreak of influenza A(H1N1)pdm.¹ The state of Gujarat was especially affected. Between 1 January and 22 February 2015, there were 3107 reported A(H1N1)pdm cases and 207 reported deaths, with more believed to be unreported. By comparison, during the whole of 2014, there were 157 cases and 55 deaths reported.²

The state capital of Ahmedabad is a major health-care centre for western India, and is well connected with neighbouring states such as Rajasthan and Madhya Pradesh, which were also severely affected by the influenza outbreak. At the beginning of November 2014, Ahmedabad had about 100 isolation beds in government-run hospitals, about 25 isolation beds in major private hospitals and fewer than 20 paediatric isolation beds in the private and public sectors combined.

By January 2015, the number of cases confirmed by real-time reverse transcriptase polymerase chain reaction was increasing by almost 90 daily, and an additional 100 cases were being referred each day to Ahmedabad from other cities or states. Public anxiety was high, and newspapers were publishing daily updates on numbers of cases, deaths and hospital discharges, from the government registry. The state government policy was to allocate isolation beds to patients with severe disease requiring hospital admission. The state government increased the number of isolation beds to more than 600 in Ahmedabad and was coordinating with private hospital managers and doctors to help increase capacity. Private hospitals increased their capacity to around 100 isolation beds. The resultant situation was extremely challenging with regard to coordination of patients and availability of isolation beds.

As an innovative solution to the immediate needs for coordination, a group of private intensive-care physicians decided to use the WhatsApp Messenger cross-platform application to facilitate communication between key stakeholders. WhatsApp is a smartphone app in which up to 100 people can be part of one group and one person can be part of any number of groups. The app allows sharing of links, pictures and other media, in addition to live chat and call facilities. We selected WhatsApp because it is widely used in India. Four administrators controlled overall data-sharing, to ensure maintenance of patient privacy. We created a core group, consisting of 16 adult and paediatric intensivists and

other doctors in private hospitals involved in managing patients infected with influenza A(H1N1)pdm. Each core-group doctor created their own WhatsApp group of their referring physicians/paediatricians, including those from outside Ahmedabad. Around 100 doctors used the service of this WhatsApp system. The core group coordinated with government hospitals equipped with isolation and testing facilities. Through this two-tier network, a range of information was shared, including: daily updates on the number of isolation beds available in all major hospitals, with near real-time updates of empty-bed status; daily updates on the availability of invasive/non-invasive ventilators and extracorporeal membrane oxygenation machines; regular updates on and discussion of complex cases; a list of pharmacies with stocks of oseltamivir and influenza vaccine; and a list of government hospitals testing for influenza A(H1N1)pdm, together with their batch timings.

Patients' privacy was protected by sharing only non-identifiable laboratory and imaging reports. Use of WhatsApp enabled easy information-sharing among doctors – and even with patients – in real time. We found we could share radiographs and computed tomography scan reports more efficiently than by, for example, email. In addition, the WhatsApp system facilitated discussion of results with specialists.

In this example, social media provided a simple information-sharing platform between practitioners. Anecdotally, we are aware that the strategy helped many doctors and patients, through improved coordination. The outbreak underscored India's need for strong influenza surveillance, outbreak preparedness and response, plus vaccination for high-risk groups.¹

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There has been an increased interest in use of social media as an effective communication tool for crisis and risk management.³ Regulatory issues and a lack of guidance on appropriate use have perhaps led to reluctance to use social media. For example, in the context of social media in clinical care, key concerns about the privacy of patient data have been debated and the need for bespoke, secure platforms emphasized.⁴

Use of social media for disease surveillance and outbreak management was the subject of a recent systematic literature review.⁵ The authors identified only a few scientific studies published to assess the performance of social media in this context. The review authors suggested that this may be because of difficulties in translating research that uses social media for biosurveillance into practice, plus the current lack of an ethical framework to integrate social media into public health surveillance. Nevertheless, the review demonstrated some evidence that data on social media could facilitate real-time surveillance of health issues and outbreak management.

We plan to keep the WhatsApp groups active and develop more formal protocols to facilitate responses to future emergencies; we would also like to involve more doctors across neighbouring states. Based on our experiences, we recommend further investigation of the potential role of social media during such public health events.

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Inside

Editorial

Making “prevention and preparedness” a recovery priority: lessons from the response to the 2015 Nepal earthquake 107

Review

Opportunities and obstacles in child and adolescent mental health services in low- and middle-income countries: a review of the literature 110
Dutsadee Juengsiragulwit

Original research

HIV drug-resistance early-warning indicators and quality care in India: preliminary findings from a pilot study in Pune city 123
Manisha Ghate, Dileep Kadam, Nitin Gaikwad, Subramanian Shankar, Shraddha Gurav, Girish Rahane, Sukarma Tanwar, Bharat Rewari, Raman Gangakhedkar

Lessons for addressing noncommunicable diseases within a primary health-care system from the Ballabgarh project, India 130
Ritvik Amarchand, Anand Krishnan, Deepika Singh Saraf, Prashant Mathur, Deepak K Shukla, Lalit M Nath

Regional variation in maternal and childhood undernutrition in Bangladesh: evidence from demographic and health surveys 139
Masuda Mohsena, Rie Goto, CG Nicholas Mascie-Taylor

Exploring the factors that influence the perceptions of disability: a qualitative study of mothers of children with disabilities at a community-based rehabilitation centre in Sri Lanka 150
Michel D Landry, Sudha R Raman, Elise Harris, Layla Madison, Meera Parekh, Cecile Banks, Huda Bhatti, Champa Wijesinghe

Tobacco-promotional activities in rural Sri Lanka: a cross-sectional study of knowledge, exposure and responses among adolescent schoolchildren 159
E Madhurangi Perera, Nalika S Gunawardena

Access to free health-care services for the poor in tertiary hospitals of western Nepal: a descriptive study 167
Preeti K Mahato, Giridhari Sharma Paudel

HIV prevalence in blood donors and recipients in Pakistan: a meta-analysis and analysis of blood-bank data 176
Bushra Moiz, Barkat Ali, Muhammad Hasnain Chatha, Ahmed Raheem, Hasan Abbas Zaheer

Policy and practice

Feasibility of implementing an integrated tool for improvement of treatment quality and early-warning indicators for HIV drug resistance: a pilot study of centres in India 184
Bharat B Rewari, Nicole S Seguy, Sukarma SS Tanwar, Po-Lin Chan, Vimlesh Purohit, Pauline Harvey, Dongbao Yu, AS Rathore

Impact of rubella vaccination on elimination of congenital rubella syndrome in Sri Lanka: progress and challenges 189
Deepa Gamage, Geethani Galagoda, Paba Palihawadana

Towards elimination of parent-to-child transmission of syphilis in India: a rapid situation review to inform national strategy 197
Vani Srinivas, Prasad LN Turlapati, Anil K Bhola, Aman K Singh, Shobini Rajan, Radha S Gupta, Sunil D Khaparde

Landscaping capacity-building initiatives in epidemiology in India: bridging the demand-supply gap 204
Sanjay Zodpey, Anuja Pandey, Manoj Murhekar, Anjali Sharma

Letter

Innovative use of social media platform WhatsApp during influenza outbreak in Gujarat, India 213
Bhagyesh Shah, Shuchi Kaushik



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