

Examining the Factors Impacting Integrated Service Delivery in Leprosy Elimination Programs in Bihar

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The disease control program is critical to the agenda of social justice. A generalist approach to the disease control program involves understanding its complexity and prevention from various perspectives, including ecological theory. The integration of the disease control program into the existing healthcare delivery system has been advocated over many decades, with an emphasis on the medical model of disease control. Integration has been widely considered as a means to achieve an effective and efficient health system. This approach has been widely adopted in low-middle-income countries to integrate vertical programs such as leprosy, malaria, HIV/AIDs, and others. However, studies suggest that there is a lack of evidence about the effectiveness of health system integration. The available evidence shows that integration of the health system can have a mixed, negative, or no impact on the health system. This growing enthusiasm toward health system integration is primarily based on the perceived benefits of an integrated approach. This discussion paper draws on the experience of the integration of the National Leprosy Elimination Program in India. It highlights the factors that affected the integration of leprosy programs in Bihar and also affected the pursuit of social justice for people who have been marginalized in our modern world.

Keywords: *integration, health system, leprosy, India, ethic*

Introduction

Implementing a leprosy disease control program is essential to achieve social justice for persons with leprosy. In developing countries where leprosy prevalence is still high, effective prevention strategies are needed to ensure that patients have

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access to healthcare services (WHO, 2020) along with addressing wider social factors. In the era of healthcare reform, efforts to integrate disease control programs with health systems in low- and middle-income countries have focused on improving access to care and healthcare outcomes while simultaneously reducing costs (Rankin & Campbell, 2009). An integrated approach to the delivery of health services has been proposed as a means to achieve a cost-effective and efficient health system (Armitage, Suter, Oelke, & Adair, 2009; Atun, De Jongh, Secci, Ohiri, & Adeyi, 2009; Suter, Oelke, Adair, & Armitage, 2009), by improving effective communication and internal processes (Coddington, Ackerman, & Moore, 2001). Scholars have argued that integrated healthcare strategies can improve benefits, quality of care, organizational performance, and patient-level outcomes (Armitage et al., 2009; Evans, Baker, Berta, & Barnsley, 2013; Strandberg-Larsen & Krasnik, 2009; Suter et al., 2009). These strategies can lead to reduced costs, improved patient satisfaction, better disease management, and improved population health outcomes (Armitage et al., 2009; Evans et al., 2013; Strandberg-Larsen & Krasnik, 2009; Suter et al., 2009).

Despite growing recognition of the potential benefits of an integrated approach to health services, the implementation of such services in resource-poor settings has faced numerous challenges. Empirical studies on the integration of leprosy programs in India have concluded that the integration of leprosy programs into the general health system resulted in an increase in new case detection (Rao et al., 2002; Parkash et al., 2003; Rao, Gift, Rao, Samuel, & Bushanam, 2002). However, the same integration caused a decline in follow-up, monitoring of treatment completion (Rao et al., 2002), and adherence to the treatment protocol (Parkash et al., 2003). This highlights that the assumption and underlying principle of adopting an integrated approach is weak and flawed and requires careful examination. In this paper, we discuss why the integration of leprosy prevention services is failing in Bihar, India. We also reflect on the various factors that have contributed to the slow progress of the leprosy control program in Bihar, including reduced outreach services, shortage of health workers, community participation, and program priority at the state and the national level.

Leprosy: A Stigmatized Disease

Leprosy is an ancient, debilitating, and highly stigmatized disease that still affects millions of people around the world, particularly in countries such as India. Bihar, a state in north India, is one of the states that report the highest prevalence of leprosy in the country. In Bihar, there is a lack of access to quality healthcare services and education, as well as inadequate resources to meet the needs of those affected by leprosy. Many patients have not been able to access the necessary treatment due to cost, fear of diagnosis, territorial access, uncertainty about treatment delays (Cavalcante, Larocca, & Chaves, 2020; Nicholls, Wiens, & Smith, 2003; Zaw et al., 2020), and the unaffordable cost of medications and transportation to hospitals (Atre, Rangan, Shetty, Gaikwad, & Mistry, 2011). This has resulted in

individuals living with leprosy for longer periods and being unable to access the services they need to stay healthy. The impact of leprosy on social development is far-reaching. This is an unacceptable situation and a denial of the right to health. There is a high prevalence of stigma toward leprosy patients (Noordende et al., 2021), which results in discrimination and social exclusion (Link & Phelan, 2001; Weiss, Ramakrishna, & Somma, 2006). Patients with leprosy are viewed with abhorrence, ostracized, and subjected to inhuman treatment (Desikan, 2012). Leprosy has a huge impact on patients and their families with a drastic reduction in income, further pushing them into deep poverty and isolation (Chandler et al., 2015).

In December 2005, the Government of India declared the elimination of leprosy by achieving the prevalence rate target of less than 1 per 10,000 of the population. However, the decision was criticized for its accuracy and choice of selected target indicators (Feenstra, 2003). In 2010–11, among the global 2.32 lakh cases of leprosy, India had a share of 1.35 lakh cases (58%) (ILEP, 2013). The new annual case detection rate in India is 0.97 per 100,000 of the population. The prevalence rate of leprosy was 0.69 per 10,000 in 2010–11, similar to the prevalence rate in 2014–15 (Central Leprosy Division, 2016). Between 2010 and 2015, the prevalence rate was more or less the same. Of 640 districts, 209 of those were identified as high-endemic districts in 2012–13. Bihar, a high-endemic state, accounts for more than 11% of new cases detected with a prevalence rate of 1.2 per 10,000 of the population (GoI, 2013). Although leprosy elimination has been achieved, annual case detection rate remains at the same level (WHO, 2012). This is a warning sign and an indication to actively identify new cases and treat them to achieve leprosy eradication.

In 2016, the Government of India launched a unique approach, that is, a leprosy case detection campaign (LCDC) to identify and detect leprosy cases in the community. The program aimed to identify hidden cases and detect them early to stop the transmission of the disease in the community. This approach was adopted due to the fact that the previous integrated approach to the leprosy program failed to achieve its goal. Integration of leprosy elimination services can ensure service availability or coverage, but may not ensure access to healthcare services due to various contextual and systematic factors and determinants. The assumption, underpinning integrated programming, that the general health system will overtake the responsibility of vertical program seems to be problematic and requires further examination.

Integration of Leprosy Elimination Services

The Alma Ata declaration of 1978 was a milestone in the history of international social development. It aims to bring primary health care for all, and provide equitable access to health services for all people around the world (WHO, 1978). The integrated approach was emphasized in the declaration to provide comprehensive primary health care by involving inter-sectoral coordination to

address social determinants of health. The declaration reaffirmed the WHO's definition of health and emphasized the three main ideas for primary health care (PHC): use of appropriate medical technology, community participation, and an inter-sectoral approach to health (WHO, 1978). The ideas of community participation and an inter-sectoral approach to health are key for social development that focuses not only on the individual but also on community involvement at all levels including participation, advocacy, planning, and decision. The declaration advocates universal access to health care and emphasizes its need as an essential human right based on the principles of social justice. However, the Alma-Ata declaration received criticism and reactions throughout the world. Whilst few condemned it for being unrealistic, idealistic, and too broad (Cueto, 2004), others contended that the idea of a comprehensive PHC approach was never truly tested (Magnussen, Ehiri, & Jolly, 2004). Very soon selective PHC approach dominated the primary healthcare models. Many countries adopted the selective PHC approach and implemented vertical programs for control and prevention of malaria, HIV/AIDS, dengue, schistosomiasis, leprosy, and tuberculosis (Atun et al., 2009). Apart from the disease-specific program, the selective approach was adapted to deliver preventive healthcare services to address malnutrition, family planning, and immunization.

Similarly, to other countries, Indian health policy was influenced by the selective approach and many health and family programs were launched to address health issues and illnesses such as reproductive and child health, family planning, tuberculosis, leprosy, malaria, and others (Ramani, Sivakami, & Gilson, 2019). The selective approach came under criticism for it was observed that these vertical programs are causing fragmentation in the health system and not addressing people's health (Atun, 2010). To reduce such a negative effect, integration of the targeted program was proposed as a strategy to strengthen the health system to address population health needs more effectively. Indian health policy was also influenced by such a shift in healthcare delivery.

Leprosy Program in India: Brief History

During colonial India, segregation of the leprosy population was used as a strategy to control the transmission of leprosy (Robertson, 2009). Further private philanthropic religious organizations became responsible for providing care and treatment of leprosy patients. The local government and charitable organizations established a new institution for people with leprosy and provided social, religious, and medical services. After independence, the Indian government launched the National Leprosy Control Program (NCLP) in 1955 to control leprosy and introduced a domiciliary treatment based on dapsone monotherapy. The treatment was implemented through vertical units and employed survey, education, and treatment (SET) strategy. In the late 1970s, leprosy was considered a curable disease with the introduction of multi-drug therapy (MDT), which was later recommended by the WHO study group in Geneva in 1981. In 1981, the Swaminathan

Committee was formed, which recognized the failure of NLCP and recommended changing leprosy control strategies to leprosy eradication strategies. NLCP was found to be ineffective and the main reason for this failure was related to poor program conceptualization, lack of scientific methodology, and lack of interdisciplinary input. Adopting these recommendations, in 1983 National Leprosy Elimination Program (NLEP) was introduced with an emphasis on the treatment and cure with MDT, which was recommended by the WHO. The main strategies under NLEP were early detection, continuous MDT treatment, intensified health education and awareness program, appropriate medical rehabilitation, and healthcare services.

In 1991, World Health Assembly adopted a resolution to eliminate leprosy by the year 2000. In this context, elimination was defined as attaining a prevalence of less than one case per 10,000 of the population. As a result, a free supply of MDT drugs was achieved worldwide. The global call for the elimination of leprosy received a huge amount of international funding, and member states were advised to mobilize political commitment to achieve the elimination of leprosy at the national level by the end of the year 2000. Fourteen countries including India missed this goal to achieve leprosy elimination. In 2001 new target, to eliminate leprosy by 2005, was set for these countries. The strategic plan for leprosy elimination 2000–2005 encouraged countries to ensure that leprosy control activities and services are available and accessible to all individuals with leprosy in the nearest health facility. Followed by the elimination of leprosy globally in 2005 a new global strategy was devised to further reduce the burden of leprosy and sustain leprosy control activities 2006–2010. In this strategic plan, the sustainability of the program was emphasized by promoting the integration of leprosy services with the general health system. Separation of leprosy elimination services was observed to have led to limited intervention and resulted in limited access to MDT (multi-drug therapy), low levels of compliance with treatment, and subsequent reregistration of these cases as “new” (World Bank, 2001). The World Bank supported the NLEP in India and emphasized the decentralization and integration of leprosy elimination services with the general health system to achieve efficacy and sustainability (World Bank, 2001).

Integration of NLEP in India

During the 9th 5-year plan (1997–2002) of India, horizontal integration of targeted programs was envisaged including NLEP. It was proposed that leprosy services will be provided through the existing general health system. The 2002 national health policy also envisaged leprosy elimination by 2005 in response to internationally set commitments. Case detection was intensified with a wider MDT coverage, laboratory services were strengthened, surveillance systems were established to monitor time trends, and a modified leprosy campaign was implemented in 1997 during this period of the plan. The leprosy elimination target was set to achieve 1 prevalence rate per 10,000 of the population. In 2004,

the NLEP leprosy program was integrated with general health services. In 2005, the National Rural Health Mission (NRHM) was launched and all national health and family welfare programs were brought together and integrated with the health system, including the NLEP. The integration was aimed to gain administrative and financial efficiency and utilize the resources through coordinated efforts. NRHM provided substantial funds and resources to poor states to improve their health indicators (Das, 2008). The integration of NLEP was carried out in two phases. In the first phase, the general health system staff was trained and during the second phase, leprosy staff was placed in the general health system. The 11th 5-year plan laid emphasis on maintaining achieved PR (prevalence rate) below one and continuing with the integrated component of the program with no vertical structures below the district level (Planning Commission, 2008).

Factor Affecting the Integrated Leprosy Program to Achieve Its Target

Voluntary Self-Reporting

The “Global Strategy for Further Reducing the Leprosy Burden and Sustaining Leprosy Control Activities 2006–2010,” proposed case detection through self-reporting. It proposed that NLEP program should ensure community awareness to encourage people to come forward for treatment and recommended integrating leprosy services to health facilities (World Health Organization, 2005). This assumption of voluntary reporting for leprosy patients has some inherent problems related to a low level of community awareness, a high level of social stigma, atypical skin lesions, and dependence on neurological symptoms that appear late (Kumar, 2015). Volunteer reporting systems are ineffective as they require individuals to disclose their health condition and sometimes risk being isolated from family and society. People with leprosy often lack the resources and knowledge necessary to prevent the disease; therefore, they may not be prepared to inform the authorities if they are infected, leading to a lack of reporting. The voluntary (self) reporting discounts the health system’s effort to actively engage in the leprosy elimination effort. It puts the burden and responsibility of the disease cure on the patients. In other terms, it shifts the responsibilities of the public financed health system to the patients to come forward and seek health services similar to other minor diseases or illnesses. Leprosy disease is very different from other types of diseases and it has long-term multiple implications for patients and the family. It should not be treated or dealt with in a similar way as other illnesses are treated like malaria, tuberculosis, and HIV/AIDS.

The adoption of voluntary self-reporting moves away from the notion of health equity and health right in the context of the argument of a low level of prevalence rate that is, 1 case per 10,000 of the population. This was widely accepted as the best way to discontinue the vertical program and use the integrated approach to control and eliminate leprosy. Conceptually, the notion of an integrated approach or integrated programming is very ambitious. However, its application varies

greatly and depends upon many contextual factors (Armitage et al., 2009; Atun et al., 2009). The integration of a leprosy program lacks the aspect of planning that resulted in the implementation of “LCDC” to identify the hidden cases of leprosy in the community in 2016.

Population-Related Factors

It has been widely researched and known that patients with leprosy experience stigma, discrimination, and rejection from their family and community (Cavalcante et al., 2020; Nicholls et al., 2003; Singh, Sinha, Banerjee, & Jaswal, 2013; Zaw et al., 2020). Their association and participation in family and community events are forcibly restricted by family members. These restrictions also lead to delays in accessing health services that result in the transmission and emergence of new cases of leprosy in the community. Even if patients identify the patch of leprosy or loss of sensation, they do not pay much attention to these early signs. They prefer to go to religious places like temples, mosques, etc. to worship. They still perceive that this disease is related to their sinful life. In other cases, they visit the local rural medical practitioners, quacks (unqualified medical practitioners), or private medical practitioners where they hardly receive the correct treatment. Challenges such as low awareness, illiteracy, and lack of capacity of community health workers are the main challenges in early detection and treatment. Also, the perceived quality of the health services at government hospitals is still considered poor. Irregular medical and drug supplies and overcrowding at public health facilities are other factors that affect the patient decision to access health care that were missing in the integrated approach to the leprosy program. These challenges were not recognized during integrated planning.

Human Resources

The public health system in India faces a severe shortage of staff, infrastructure, and medical supplies, and it is challenging for the health system to provide integrated health services (Kumar, 2020). Over a period of time, the number of leprosy experts has declined. The involvement of dermatologists in the vertical program has vanished after meeting the leprosy elimination target and integration of the leprosy program with the general health system (Kumar, 2015). In the post-integration of the leprosy program, there was a delay in identifying and diagnosing patients with leprosy (Muthuvel et al., 2017), which further led to the transmission of the disease in the community. The post of district leprosy officer was diluted at the time of program integration and the new post of communicable disease officer was created. Communicable disease officers were responsible for managing and implementing tuberculosis and leprosy program. Most of their time is spent managing and supervising the tuberculosis program.

Recent BLCC and LCDC programs for early detection were not showing much success because of a shortage of expert and experienced staff on leprosy.

These programs were supervised by nonmedical personnel. Most of the staff that had experience in handling leprosy disease were either retired or their post are vacant for a long time. And some of them have reached the retirement stage. Experts in leprosy and specialist professionals are required for the design of policies and programs for control and elimination. Their services are required for research on service delivery, drug development and research, development of training modules, and teaching courses for control and management. Professionals and physicians experienced in the management of leprosy were required to transfer their knowledge and work experience to health workers and new-generation medical students (Athreya, 2007).

Integration of leprosy elimination services along with the withdrawal of the targeted program staff raised serious ethical concerns about the marginalized and leprosy-affected population, such as denial of the right to health as a result of reduced access to health care (and termination of outreach visits). The Strong Referral System is essential to provide the continuum of care. One of the possible reasons could be the workload on front-line workers who are supposed to provide various health services to the community, such as family planning, reproductive health, tuberculosis, and others.

Health Program Priority

ASHA as a community health worker is often asked to perform multiple tasks for various programs at the community level. They are monitored and supervised by their ASHA supervisors and block health managers on a day-to-day basis for their work. In the current context, the department of health is focusing on MNCH, FP, and RI activities and instructing ASHA to undertake these activities on a priority basis. According to an ASHA, while conducting fieldwork, she said, “we don’t consider tuberculosis, leprosy or filaria as their priority task. Our main task is to work for maternal and child health in our area.” Hence, there is still a lack of attention at the state level toward the leprosy program.

Another factor that demotivates ASHA from her participation in the leprosy program is a delay in paying the incentive for the identification and treatment of leprosy cases. The government gives Rs. 850 for multi-bacillary cases and Rs. 650 for Pauci bacillary cases to ASHA upon complete treatment. The completion of the treatment depends on several factors such as the availability of drugs at the health facility, willingness to complete the treatment, and patients’ health-seeking behaviors. Additionally, in most cases, ASHAs do not receive their payment on time due to corruption and non-cooperation from the block-level staff involved in incentive payments. These interpersonal relationships between the staff and ASHAs, along with corruption involved in the incentive payment process, affect their participation in the leprosy program. Community health workers, that is, ASHAs prefer to work on higher incentive projects such as maternal and child health programs (Jannani Surksha Program) than any other programs. For the delivery under JSY program, they receive the incentive in 2 months, and for other

disease programs, their incentives are delayed by more than 6 to 8 months. Such program planning and incentive design lack understanding of the inter-program effect and the workload of community health workers. It is essential to re-assess the workload of frontline workers and build a strong referral system to provide continuous and timely services to eliminate leprosy.

Community Participation and Participation

The integrated leprosy program has been instrumental in increasing the knowledge and skills of PHC personnel to diagnose and manage leprosy cases (Siddiqui et al., 2009). However, it was also found that 26% of leprosy suspects were waiting for their confirmation for 1–8 months after their initial PHC visit. A recent study conducted by Kumar et al. (2013) in their population-based survey in two states, reveals that there are large numbers of previously undetected leprosy cases in the population and highlighted that the case detection rate is low in the community.

In the current leprosy eradication program, little emphasis has been given to community participation. Strengthening village health committees and panchayat raj institutions can facilitate this case identification process and provide the local commitment to eliminate leprosy in communities. NRHM emphasized decentralized planning and community participation in the planning process. Decentralized planning and management structure are potentially more efficient than centralized structures due to their greater capability to incorporate all information in decision-making and the potential of an overall greater system learning and innovations (Hurley, Birch, & Eyles, 1995). The current integration of the leprosy program has discounted community empowerment and only adopted the top-down approach to the integration of the health system to organize service delivery through the medical model, which includes case identification and referral to local health centers. It doesn't outline a process of community planning for the eradication of the disease. However, community and user integration are similarly equally important to provide access to services. There is limited effort or no effort to strengthen the capacity of local community members in terms of decision making and empowerment at village level. The Alma-Ata declaration and the NRHM emphasized community empowerment and community participation in decision-making and it was believed that community participation is essential in the delivery of primary healthcare services. Community and community workers are local stakeholders that are aware of local social, economic, and cultural issues that are important for planning and decision-making in the process of service delivery.

Discussion and Conclusions

Integration of the leprosy program into the general health system has its own challenges. Complete dependency on the general health system affects the activities of the leprosy elimination program. Most Indian states such as Bihar,

Uttar Pradesh, Jharkhand, Chhattisgarh, and Madhya Pradesh suffer from a severe shortage of basic health infrastructure and human resources according to Indian Public Health Standards (Rao, Rao, Kumar, Chatterjee, & Sundararaman, 2011; Karan et al., 2021). The severe shortage not only affects the efficiency of the health system but also results in poor quality of service delivery (Gill, 2016; Kumar, 2020). Also, population growth creates another challenge for the health system to provide service to the new population (Karan et al., 2021). In this context, the service provider, and health manager has to prioritize the disease control effort based on resource availability. Currently, the leprosy elimination effort is the best example to understand the implications of an integrated approach on the health system.

Poor program planning and reduced access to health care for leprosy patients is an ethical issue and raises concern for the underserved population in our society. Due to social stigma and social awareness about the identification of leprosy disease, people suffering from leprosy will not be able to come forward and self-report their disease. Our health system must assess their unmet needs, involve community members, and design health services that meet the need of the population. There is a lack of comprehensive strategies to tackle leprosy and requires a partnership between various ministries and departments (WHO, 2019). The medical model of leprosy control has been largely inadequate in tackling the challenges of leprosy in India (Siddiqui et al., 2009; Sil & Das, 2022). This failure is largely due to the limited scope of its approach, which focuses solely on treating the disease at an individual level. It ignores important social, economic, and cultural aspects, which are essential to the provision of effective and comprehensive leprosy control services. Adopting an ecological perspective to disease control programs can improve the effort to control and eliminate leprosy. Ecological perspective considers both biological and social factors that contribute to the spread of disease. It can help to understand the complex dynamics of leprosy transmission and the conditions that increase its spread. Additionally, it can help understand the role of different cultural practices and beliefs in the spread of leprosy. Some cultural beliefs that leprosy is a punishment from God make people develop negative attitudes and stigma toward patients with leprosy. Understanding the complexities between biological and social factors can help policymakers design interventions that are more likely to be accepted by the community and increase their participation in the elimination of leprosy.

Integration of the health system has been widely considered as a means to achieve a more efficient health system (Armitage et al., 2009; Atun et al., 2009; Suter et al., 2009). Contrary to this, the service integration approach in the context of the leprosy elimination program in India showed that this approach has failed to achieve its goal of efficacy and sustainability as it lacks community participation and intersectoral coordination, which is a key element of social development. This unintended consequence of the integration effort has affected the service delivery and leprosy elimination activities. Active case detection strategies, community empowerment, and their participation, strengthened referral system,

increased public health spending and geographically decentralized planning and management can further improve the leprosy elimination efforts. Government and policy planners are required to take initiatives in areas such as poverty reduction, employment generation, and stigma reduction to ensure the best possible quality of life for those affected by leprosy. Integration efforts must examine the assumptions and claims that underlie the various models against the practice to reduce its negative or unintended consequences on the health system and population.

Declaration of Conflicting Interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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