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Methodology of a large Maternal and Child Health Demographic Surveillance System (MCHDSS) in marginalized communities

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ABSTRACT

In countries where Civil Registration and Vital Statistics Systems (CRVS) are not fully established and developed, Health and Demographic Surveillance System (HDSS) play a significant role in capturing the health status of a population. This paper describes primary findings and explores the process involved in establishing the largest Maternal and Child Health Demographic Surveillance System (MCHDSS) in India. The present MCHDSS is established in Urban, Rural and Tribal settings in the State of Gujarat in 2019 by Indian Institute of Public Health, Gandhinagar. It covers 2 districts, 3 sub-districts/blocks, 132 villages, translated into 2, 31,336 individuals. The population being surveyed and monitored largely belongs to marginalized and poor communities. MCHDSS employs a prospective longitudinal survey designed to study 1) Socio-economic situations, basic household level facilities (water, sanitation, etc.) and health, 2) Current situation and longitudinal changes in the Maternal and Child health and 3) provide a platform for testing innovations and interventions for improvement in maternal and child health indicators. Large MCHDSS such as this, will not only yield conventional health and demographic dataset, it will also provide a huge platform for the innovators to field test and proof their innovations in real-life situations. Apart from ensuring data quality, setting up of future HDSS should consider other identified challenges such as retention of human resources, technical difficulties that revolve around the mode of the digital survey and maintaining relations with stakeholders.

Keywords— *Health and Demographic Surveillance System, HDSS, Maternal and Child Health Demographic Surveillance System, Maternal and Child Health*

1. INTRODUCTION

Health care systems are becoming largely dependent on information technology and real-time data to make informed decision to improve the availability and affordability of timely health care services [1]. Use of information technology in healthcare has enabled to improve healthcare quality and safety, reduce the cost of health service, and provide a platform to conduct research which, in turn, aid to reform approaches to healthcare delivery and wellness promotion [2, 3].

Information technology has also improved data collection methods in the past few decades. However, the absence of reliable demographic and health data is still a common problem in many developing countries and it is of the utmost importance when trying to understand the health of a population. In many developing countries often data is not collected routinely and many epidemiological indicators are estimates based on a census that happens once every decade. Evaluation of health needs of a population and development of healthcare interventions depends on reliable demographic data [4]. In the last few decades, there has been a rise in HDSS field sites in many developing countries. In countries where Civil Registration and Vital Statistics systems (CRVS) are not fully established and developed, these HDSS (longitudinal cohort surveys that follow people of the same geographic region) plays a vital role in capturing the health needs of a population [5].

The INDEPTH (International Network for Demographic Surveillance System) network is the largest network of HDSSs networks in the world with almost 19 members countries and 49 HDSS field sites in operation [6]. In India the INDEPTH network is operational in 3 cities; one in Ballabgarh (Haryana) [7], one in Birbhum (West Bengal) [8] and the other in Vadu (Pune) [9]. The Indian centres have been successful in collating data through periodic surveys as well as specific cross-sectional surveys to capture socio-economic conditions, vital statistics, maternal and child health, non-communicable and communicable diseases. The three

centres cover a population ranging from 60,000 to 90,000. [7–9]. HDSSs are not only capable of capturing the health needs of populations, but recent research has also suggested that these sites improve health indicators and health utilization parameters.

Existing maternal and child health surveillance systems in India suffer from poor quality as well as lack of coverage. There are many data quality issues/challenges in the national surveys (NFHS and the DLHS), tracking systems (The Mother and Child Tracking System (MCTS)) and small scale surveys conducted in India [10–13]. For instance, an evaluation report on the MCTS (one of largest MCH surveillance initiatives) revealed suboptimal training and monitoring, poor field level data collection, inefficient transfer processes and unclear guidelines. In the two evaluated states only an average of 64% of the surveys we completely filled in, there were also inconsistent accuracy rates ranging from 71% - 92%. Other issues included lack of standardized methods for data collection, processing and analysis as well a poor physical infrastructure (electricity and internet connectivity) and poor human resource management [11].

National demography survey such as the NFHS and DLHS since its inception have maternal and child health issues at the heart of the surveys but they have also been criticized for i) non-comparable estimates (capturing data in a manner that is not comparable with subsequent surveys eg: using varying reference periods) ii) delay in releasing data (NFHS and DLHS have long delays that vary from 9 to 22 months) iii) poor utilization for publication as some find published data format to be not user friendly iv) small sample size often not enough to generalize for the whole population v) poor monitoring standards and no vi) transparency in methodology [10].

Often it is essential to redesign and reform parts of the health care system when it is not functional. However, in resource-limited settings, it is a huge challenge for governments to initiate and carry out this process [14]. The quality of data available plays a significant part in this process of redesigning. Quality data plays a vital role in promoting a high standard of patient quality and maintaining good quality health services. Moreover, timely data can serve as a resource for monitoring and a platform which will enable evidence based healthcare decisions [13, 15]. Better data also equates to better policymaking. Health care policies and decisions that are data driven not only benefit from rational but would also be evidence based [15, 16]. One of the main pillars of decision making is good data, it can aid in budget allocation, identification of gaps, aid in evaluation and evolution of policy as well as validate decisions [17].

Current HDSS focuses on Maternal and Child health (from hereafter MCHDSS). The MCHDSS is one of the largest surveillance sites in the world established by the Indian Institute of Public Health Gandhinagar. The MCHDSS was initiated in 2018 in the state of Gujarat, with the aim to 1) Explore current situation of Maternal and child health 2) To generate near real-time reliable dataset 3) To provide a platform for innovation and intervention testing. Thus, the scope of MCHDSS will not be limited to research and synthesis only, but it will also present ample opportunities to field test the innovations for improving maternal and child health.

2. GEOGRAPHICAL COVERAGE

(a) Selected state of India; (b) Selected districts of Gujarat; (c) MCHDSS Location in Ahmedabad district; (d) MCHDSS location in Aravalli district

Fig. 1: MCHDSS field sites

Gujarat is one of the most rapidly growing states in the country. Of the total population of 6.04 Cr, 57.4% lived in Rural and 42.6% lived in the Urban region [18]. The primary reason to choose the state of Gujarat was due to lack of near real-time and reliable database in the state. Previous experience in conducting similar research in the area, cooperation and strong relationships with the local stakeholders and feasibility in the operation were some of the other reasons selecting the location to establish MCHDSS.

The MCHDDS is established in the subset of two districts of Gujarat; Ahmedabad and Aravalli. The urban region is represented by Behrampura and Vasna wards of Ahmedabad city. Bavla block is considered a Rural region based on its socio-economic characteristics and lack of connectivity to major developing regions. Bhiloda, Meghraj and Modasa blocks of Aravalli district were considered as Tribal regions.

3. METHOD

The longitudinal prospective study design was employed to establish the current MCHDSS. In order to ensure statistically significant sampling design and representativeness of regions being surveyed, we consulted experts from various disciplines MCH, food & nutrition, public health, demography and bio-statistics. The household is considered as the basic survey unit for collection demographic and health information, and currently, pregnant mothers and children below 5 years of age from the baseline survey forms the sampling frame for the second wave of the survey for mother and child.

Baseline (1st wave) survey inquired and collected information associated with socioeconomic standing (Caste category, house type, Household (HH) assets, water source, sanitation facility, family income, occupation type etc.) and health variables (presence of currently pregnant women, children under 5 years of age, illness). Each household was assigned a unique household ID, generated based on geographical location (district, block and village). Mother and Child health (second wave) surveys are administered using two separate detailed questionnaires. To maintain the longitudinal nature of the database, a corresponding unique ID is assigned to each currently pregnant women based on her HH ID. Similarly, the Child's unique ID is created based on her Mother's unique ID. Such an interconnected structure of assigning unique identifier will allow analysing Maternal and Child health data with respect to their socio-economic conditions as well. Questionnaire to understand Maternal health situation, information about obstetric history, complication before, during and after pregnancy, preference for service provider, treatment for complications etc., and Child's questionnaire records information related to nutrition, feeding practice, immunization, illness etc. 2nd wave of survey for maternal and child health initiated from December 2018. And follow-up surveys are planned to be routinely conducted at the interval of 3 months after 2nd wave of MCH survey.

3.1 Population characteristics

Table 1: Distribution of total Household surveyed and total no. of Individuals by region

Region	Total surveyed Household	Total individuals	Avg/no of individuals per HH
Urban	20,235	88,344	4.4
Rural	19,358	66,377	3.4
Tribal	17,201	76,615	4.5
Total	56,794	231,336	4.1

As of 3rd April 2019, a total of 56794 households have been surveyed which covers a total population of 231336 individuals. Overall on an average, each household had approximately 4 people. Notably the average number of people in a household in Urban and rural were almost similar whereas in rural it was much lower (3.4 per household) (table 1).

Table 2: Socio-economic characteristics by region (n = 56,794)

	Urban (n=20235)	Rural (n=19358)	Tribal (n=17201)	TOTAL (n=56794)
Head of the HHs				
Male	74.3	74.2	88.7	78.6
Female	25.7	25.8	11.3	21.4
Caste				
SC %	46.3	14.7	4.6	22.9
OBC %	40.4	84.3	27.8	51.6
ST %	1.2	0.1	63.2	19.6
Gen %	11.8	0.9	4.4	5.8
Ration card				
APL card	59.7	60.4	34.2	56.0
BPL card	25.1	35.4	63.7	43.3
Antoday Ann yojna card	0.3	0.3	1.5	0.7
House type				
Pucca	67.3	51.3	30.9	50.8
Kuchcha-pucca	31.9	48.5	35.6	38.7
Kuchcha/No house	0.9	0.2	33.5	10.5
Sanitation facility				
Own flush toilet	93.4	63.2	0.7	55.0
Shared/public flush toilet; own pit toilet	4.9	1.6	45.1	16.0
Shared/public pit toilet	0.7	0.6	7.6	2.8
No access to toilet/use outside, behind the bush	0.9	34.6	46.6	26.2

Of the surveyed households on an average one-fifth of them had a female head of the house and rest four-fifth a male household head. In urban and rural the approximately three quarters (74%) of the households had a male head. In comparison, more tribal households (89%) had a male head.

Overall a little over half (51.6%) of the total household were of OBC caste category, followed by SC (22.9%), ST (19.6%) and the General (5.8%). In the Urban region, most household either belonged to SC category (46.3%) or the OBC category (40.4%). In rural a large majority (84.3%) belonged to the OBC category. Unlike rural and urban region most of the households (63.2%) in the tribal belonged to the ST category (table 2).

Overall, a good proportion of the households had a ration card over half, 56.0% an Above Poverty Line (APL) card and more than 40% Below Poverty Line (BPL) card. Approximately 60% of the households in Urban and rural had an APL card. More rural households (35.4%) had BPL cards than the urban (25.1%). Comparatively, a larger proportion of the tribal households (63.7%) held a BPL card than an APL card (table 2).

Among the surveyed households only 50.8% of them lived in a pucca house, 38.7% of them lived in kutcha-pucca house and the 10.5% in a kutcha/no house. In the urban region most lived in a pucca house. In rural almost equal proportions lived in a pucca and kutcha-pucca house. In tribal the distribution was almost equal in all categories. The highest proportion (33.5%) of people living in kuctcha/no house was also found in the tribal region (Table 2).
Sanitation facility was good in the urban region where almost all, 93.4% of them had their own flush toilets. Comparatively, in rural a lower proportion had their own flush toilet, 63.2%. Many in the rural 34, 6% reported having no access to any toilet facility. In the tribal region also similar to the rural a large number 46.6% reported to having no access to a toilet facility and 52% also reported to having access to either a shared toilet, pit toilet or a public toilet (table 2).

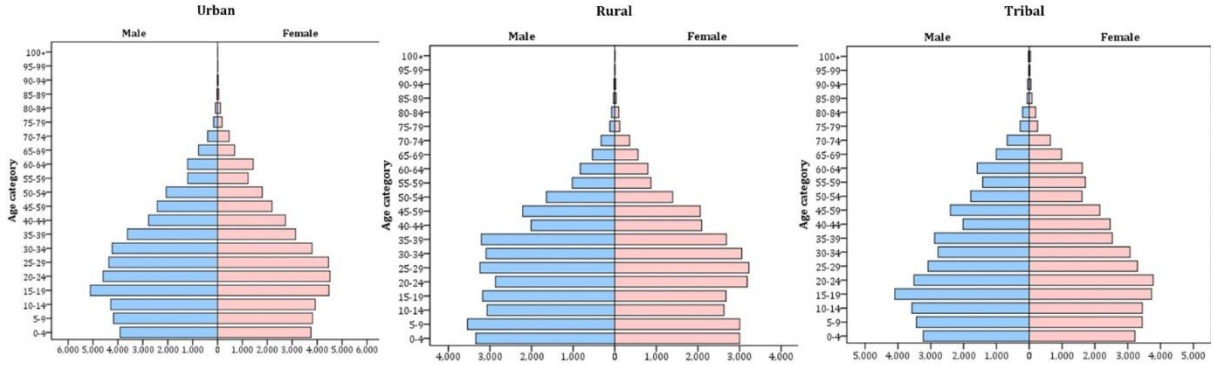

Fig. 2: Population pyramid by region

Urban and Tribal population has a comparatively smaller proportion of the young population as compared to the rural population. Across all communities, narrow head of population pyramid indicates high death rate resulting from the low proportion of people living in old age. Largely communities are characterised by low birth rate and high death rate.

3.2 Quality control

HDSS is a very complex system of large scale data-collection in the longitudinal time frame. Maintaining data quality is the most significant aspect of the process. To ensure the data quality several mechanisms are put in place. One of them is, frequent resurveying households randomly by the surveyor other than the one who surveyed for the first time. Routine descriptive analysis to enlist outliers and re-verify on the field. In addition to that, to control the human error in data entry, a customized android based application was developed. The app sets logical and consistency validation which restrict the surveyor to enter an invalid code or numeric values.

Other than a human error in data collection, surveyor's understanding of the subject and so of the questionnaire also contribute to the overall data quality. To overcome this issue and limit the erroneous collection of data, qualification criteria of nursing background (B.sc Nursing/social science) was set for the recruitment of surveyors. Furthermore, it was preferred to hire female candidates, in order to address the hesitation by the respondents. This is because follow-up surveys largely involve female respondents.

In the pilot testing phase, surveyors were given orientation training and provided sufficient hands-on experience with the application based data collection to get familiarize with the questionnaire as well as the functioning of the application. Pilot test data was then also used to evaluate surveyor's data collection accuracy and efficiency.

3.3 Monitoring and data management

When dealing with the large scale data, only ensuring data quality does not ascertain reliable results. Establishing an HDSS is a perennial process. A mechanism for data monitoring, cleaning and management was set-up from the inception of the survey. It is the 5 stage process. 1. Data is downloaded routinely from dedicated server 2. To enlist errors and outliers, descriptive analysis is performed by data management team 3. The list of data errors is shared with the supervisor (the connecting link between the surveyor and data management team) 4. Supervisor re-verify the data on field and reverts with the correction 5. Validated and cleaned data is archived in the central data management unit.

4. DISCUSSION

One of the major strength of the MCHDSS is that it will periodically provide quality data related obstetric history, ANC and PNC care utilization, child feeding and immunization practices, anthropometric measurements, institutional health care practices and preferences, complications, treatment types and service providers etc. In addition to a number of cross-sectional surveys that will be carried out, innovations testing is also an integral component of MCHDSS. ToucHb is one of the innovations which is being tested. The device measures the level of Haemoglobin in a non-invasive manner. It detects anaemia without a needle poke, and by identifying the presence of pallor in the conjunctiva. ToucHb not only focuses on the easy functionality factor but also on the affordability factor**.** Furthermore, to reduce the malnutrition among children and to curb anaemia among women, interventional studies are also being designed. Establishing HDSS in such diverse frame of socio-economic settings will provide an ideal sampling frame for future research and interventional studies.

To establish and maintain an HDSS is not an easy task and it requires strenuous efforts. From a management point of view, financial resources, human resource management, prolonged stakeholder relationship are some of the key components for the successful establishment of an HDSS [4].

First and foremost, was the selection of local NGOs which have extended the grassroots experience and strong hold and connection with the local community to carry out the survey. As it was the longitudinal survey, prolong affiliation with the selected NGOs was also one of the major concern.

Aravalli district, which is marked by undulating terrain and unpaved roads, has widely scattered households. With comparison to the other two field sites, it requires almost half an hour to reach successive HH for the survey. This somehow hampers the efficiency of data collection. In addition to that, during the survey household members are not always available. And in many cases even if House members are at home, often busy and unable to spare time to respond for the survey. In these situations, the particular households are revisited.

One of the reason for reluctance by some respondent was that many other groups may have recently conducted a survey in the same area. Under MCHDSS, the population also benefited by receiving vital health care information (eg: anthropometry measurements) and brief counselling. This, in turn, gave a kind of service satisfaction and increase acceptance of the survey.

Successful transition from hard copy form survey to the digital survey was challenging task too. Before deploying the application, it was tested by the data management team prior to introducing it to the surveyors. Data collectors and field level supervisors were given hands-on training along with the class room orientation training during the pilot phase to check the stability and correctness of the application and also the accuracy and efficiency of the surveyors.

4.1 Recommendations for future HDSS

For studies that require follow-ups, it might be useful to employ a retention strategy which will help to reduce drop-out rates. Continued support, refresher training sessions and regular monitoring for the data collectors and field supervisor is vital to ensure the quality of the data collected. It also is key that data collectors are summarized with data trends and findings during the data collection process, these sessions could also help them gain a better insight into the project and instil a sense of ownership. A good rapport and trusting relations between the participants and data collection team is key to ensure acceptance and willingness to cooperate. For longitudinal studies of long-term, it also is significant that the participants benefit from the study in the short term. Giving medical advice and sign posting people to certain services are some strategies that could be adopted. However, this might difficult in reality as it would require medically trained professionals.

5. CONCLUSION

HDSS (Health Demographic and Surveillance System) is an excellent scientific infrastructure for establishing population impacts of health interventions, in particular, those that affect large proportions of the population and effective data management can substantially enhance the scientific opportunities to establish the impacts of treatment on outcomes [19]. In the absence of a vital registration system, HDSS can play a vital role in understanding the health needs of a population. There is an urgent need in India to establish data banks which will allow the collection of real-time data that will help initiate actionable response as well as understand epidemiological trends.

Through the establishment of the largest HDSS site in western India we identified many challenges such as retention of human resource, technical difficulties that revolve around mode of digital survey, establishing and maintaining connections with local NGOs, demanding task of ensuring the data quality and timely rectification and scattered housing and meagre connectivity especially in tribal regions. For successful establishment of future HDSS site of this scale, these issues need to be considered beforehand.

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