

Noncommunicable Diseases Risk Factor Surveillance: Experience and Challenge from India

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ABSTRACT

Noncommunicable diseases (NCDs) are reaching epidemic proportions worldwide and in India. Surveillance of NCD risk factors are therefore needed as they could help in policy planning and implementation of preventive measures. This article will focus on the experiences gained, and challenges faced, in conducting NCD risk factor surveillance studies in India. Two major surveillance studies on NCDs were conducted in India – the World Health Organization (WHO) – Indian Council of Medical Research (ICMR) NCD risk factor surveillance study and the Integrated Disease Surveillance Project (IDSP). The WHO-ICMR study was a six-site pilot study representing six different geographical locations in India with a sample size of 44,537 including rural, peri-urban/slum and urban. Phase I of the IDSP was completed and included seven states in India with a sample size of 5000 per state. The NCD risk factor surveillance showed that high prevalence of diabetes, hypertension and obesity in urban areas with slightly lower prevalence rates in semi-urban and rural areas. There are several challenges in obtaining data on NCD risk factors, which include challenges in obtaining anthropometric and blood pressure measures and in assessing tobacco consumption, diet and physical activity. The challenges in field operations include contacting and convincing subjects, creating rapport, tracking subjects, climatic conditions, recall ability and interviewer skills. Success in surveillance studies depends on anticipating and managing these challenges. **Conclusion:** Improving country-level surveillance and monitoring is a valuable step in prevention and control of NCDs in India.

Keywords: Challenges, diabetes, IDSP, India, noncommunicable diseases, risk factor surveillance

Introduction

The prevalence of noncommunicable diseases (NCDs) are reaching epidemic proportions worldwide. NCDs are the leading causes of death globally, killing more people each year than all other causes combined.⁽¹⁾ Of

the 57 million deaths that occurred globally in 2008, 36 million (almost two-thirds) were due to NCDs, comprising mainly cardiovascular diseases, diabetes, cancers and chronic lung diseases.⁽¹⁾ Sadly, almost 80% of those deaths occur in developing countries.⁽²⁾ NCDs, once considered “diseases of affluence”, are now common even in low and middle income countries. An epidemiological transition model that was introduced 30 years ago is often applied to explain the differences in occurrence of diseases within and between countries. It proposes that disease patterns shift over time so that infectious and parasitic diseases are gradually, but not completely, displaced, as NCDs become the leading causes of death.⁽³⁾

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The burden of NCDs has an impact not only on the quality of life of the affected individuals and their families, but also on the country's socioeconomic status. The World Health Organization (WHO) estimates that there could be considerable loss of national income of different countries due to NCDs. It is estimated that China, India and the United Kingdom are projected to lose \$558 billion, \$237 billion and \$33 billion, respectively, from 2005 to 2015 as result of the burden of NCDs.⁽⁴⁾

Changes in diet and lifestyle that have occurred with industrialization, urbanization, economic development and market globalization, have accelerated over the past decade. These have had a significant impact on the health and nutritional status of populations, particularly in developing countries, like India. Efficient preventive strategies, including measures to control risk factors like tobacco, alcohol, obesity, blood pressure, diet and physical inactivity are needed. In India, huge increases in prevalence of diabetes, hypertension, obesity and cardiovascular disease have been reported through several studies conducted all over the country.⁽⁵⁻⁹⁾ Surveillance of NCD risk factors could significantly contribute to the policy planning and implementation of preventive measures. Surveillance is defined as the continuing scrutiny of all aspects of the occurrence and spread of a disease that are pertinent to its effective control.⁽¹⁰⁾ This article will focus on the two major NCD risk factor surveillance studies conducted in India and the experiences and challenges faced in conducting these studies.

Ncd Risk Factor Surveillance in India

The growing burden of NCDs represents a major challenge to health development in India and accurate data are vital to curb the morbidity and mortality due to NCDs. Two major surveillance studies on NCDs have been conducted in India: (i) the WHO-ICMR NCD risk factor surveillance⁽¹¹⁾ and (ii) the Integrated Disease Surveillance Project (IDSP).⁽¹²⁾

The WHO-ICMR NCD risk factor surveillance

Recognizing the lack of a national NCD surveillance system in the country, the Indian Council of Medical Research (ICMR) planned and coordinated a six-site pilot study, from 2003 to 2006, which provided the experience for developing a national strategy for the country. This was a collaborative effort of the WHO and ICMR to develop a sustainable system for NCD risk factor surveillance in India using the WHO STEPS approach. The national NCD risk factor surveillance was conducted in six different geographical locations namely Ballabgarh and Delhi (North), Chennai (South), Trivandrum (South), Dibrugarh (East) and Nagpur (Central).⁽¹³⁾

The WHO STEPwise approach to surveillance of NCDs is based on sequential levels of surveillance of different aspects of NCDs, allowing flexibility and integration at each step by maintaining standardized questionnaires and protocols to ensure comparability over time and across locations. A minimum of 2500 subjects aged between 15 and 64 years stratified by sex and 10-year age groups were studied in each of the areas (rural, peri-urban/slum and urban) at each of the six sites. The total sample size was 44,537 including rural (13,527), peri-urban/slum (15,763) and urban (15,247). Step 1 included self-reported information obtained by a questionnaire with information on demography of individuals including age sex, marital status, education, and occupation, the behavioral information including tobacco use, alcohol consumption, diet, physical activity, history of raised blood pressure and history of diabetes. Step 2 included physical measurements of individual such as height, weight, waist circumference, blood pressure and pulse rate. Step 3 included objective information by blood samples for biochemical analyses that included blood glucose and blood lipids.

Brief results on NCD risk factors from WHO-ICMR surveillance

Smoking: Smoking was most common among peri-urban/slum men (34.3%) compared to their rural (26.7%) and urban (26.5%) counterparts.

Alcohol: Alcohol consumption was more prevalent among men. About 33% of urban men, 49.3% of peri-urban/slum men and 40.5% of rural men were found to be current users of alcohol.

Physical activity: More than 50% of the urban residents, 41.4% of peri-urban/slum residents and 35% of rural residents had a sedentary lifestyle while 25.4% of rural residents, 14.2% of peri-urban/slum residents and 7.4% of urban residents were involved in vigorous physical activity.

Fruit consumption: The proportion of subjects who never consumed fruits (in the last week) were 24% in urban, 29% in peri-urban/slum and 41% in rural area.

Obesity: Obesity and abdominal obesity were more common in urban residents, followed by peri-urban/slum and lowest among rural residents. Generalized obesity: Urban (men: 30.7%, women: 38.8%), peri-urban/slum: (men: 16.7%, women: 26.1%) and rural (men: 9.4%, women: 14.1%). Abdominal obesity: Urban (men: 30.9%, women: 57.8%), peri-urban/slum: (men: 17.9%, women: 41.1%) and rural (men: 12.2%, women: 29.6%).

Diabetes: Diabetes was diagnosed based on self-reported diabetes diagnosed by a physician. The lowest

prevalence of self-reported diabetes was recorded in rural (3.1%) followed by peri-urban/slum (3.2%) and the highest in urban areas (7.3%).

Hypertension: The prevalence of hypertension was highest among urban residents (self-reported: 15.1%, newly-diagnosed: 19.3%), followed by peri-urban/slum (self-reported: 9.9%, newly diagnosed: 20.8%) and rural residents (self-reported: 7.2%, newly diagnosed: 17.4%).

The integrated disease surveillance project

The ICMR was identified by the Ministry of Health and Family Welfare, Govt. of India as the nodal agency to implement the NCD risk factor surveys under the World Bank supported Integrated Disease Surveillance Project (IDSP) in 29 states and Union Territories in 3 phases. It was planned to conduct periodic community-based surveys of the population aged 15–64 years to provide data on NCD risk factors. The first phase of the survey included seven states namely Andhra Pradesh, Kerala, Madhya Pradesh, Maharashtra, Mizoram, Tamil Nadu and Uttarakhand. It was also proposed that subsequently, the states will repeat these surveys every 3 yearly through their own resources. It was believed that this would help the state health administrators to plan strategies for the control of NCDs by modifying the risk factors.

A representative sampling design was used to obtain state-level prevalence of tobacco, alcohol, fruits, vegetable consumption, physical activity, blood pressure and body mass index. Men and women aged 15–64 years residing in urban and rural areas were included in the survey. The sample size consisted of 5000 subjects, each selected randomly from the selected households using KISH method of selection. WHO STEPS methodology for NCD risk factor surveillance has been adopted for the survey. The survey implementation was through a network of reputed institutions. This surveillance helped generate useful inputs to the recently launched government project, the National Program on Prevention and Control of Cardiovascular Diseases, Diabetes and Stroke for instituting appropriate interventions.

Brief results on NCD risk factors from IDSP (Phase I):

Tobacco: Prevalence of tobacco use in any form (smoking or smokeless) was high in Mizoram (68%) followed by Madhya Pradesh (47%), Maharashtra (37%) and Uttarakhand (27%).

Alcohol: The alcohol consumption at least once in last one year among males varied from a high 37% in Andhra Pradesh to a low 21% in Mizoram. The alcohol consumption among females was low in all the states.

Physical activity: The proportion of subjects in low

category of physical activity were 42% in Madhya Pradesh, 66% in Tamil Nadu, 67% in Uttarakhand, 68% in Andhra Pradesh, 81% in Maharashtra, 71% in Mizoram and 76% in Kerala.

Fruits consumption: The proportion of subjects consuming less than five servings of fruits or vegetables per day were 99% in Tamil Nadu, 89% in Uttarakhand, 88% in Andhra Pradesh, 87% in Kerala, 85% in Mizoram, 83% in Madhya Pradesh and 76% in Maharashtra, which was inadequate as per WHO recommended standards.

Obesity: The prevalence of overweight was high in Kerala (27%) followed by Tamil Nadu (23%) and Andhra Pradesh (19%). The prevalence of central obesity was 43% in Kerala, 25% in Tamil Nadu, 18% in Uttarakhand, 14% in Andhra Pradesh and Maharashtra, 12% in Mizoram and 11% in Madhya Pradesh.

Diabetes: Self-reported cases of diabetes were reported to be low – 1% in Mizoram, Madhya Pradesh and Maharashtra and high (6%) in Kerala.

Hypertension: The self-reported cases of hypertension ranged from 2% in Madhya Pradesh to 9% in Kerala.

ICMR-India diabetes study (ICMR-INDIAB)

A national study on diabetes called as the ICMR-INDIA DIABETES (ICMR-INDIAB) study⁽¹⁴⁾ is currently underway and this is a cross-sectional survey involving adults aged ≥ 20 years. It is being planned to be conducted in phased manner and the completed Phase I (November 2008 to April 2010) includes three states randomly selected to represent the south (Tamil Nadu), west (Maharashtra) and east (Jharkhand) of India and one UT representing northern India (Chandigarh). This study is the first effort from India to estimate national prevalence of diabetes and prediabetes,⁽¹⁵⁾ surveying rural and urban inhabitants across whole states of India.

Challenges in Obtaining Data on NCD Risk Factors in Surveillance Studies

Undoubtedly, NCD risk factor surveillance can provide valuable data on the present and future trend in NCDs in the country. However, there are several challenges in obtaining data on NCD risk factors and these are briefly summarized below

Challenges in anthropometric measurements

Anthropometric variables, particularly weight and height, are the most commonly employed measures of nutritional status in epidemiologic studies because of their simplicity and ease of collection. Anthropometric indicators are robust and easily obtainable predictors at the individual and population level of subsequent morbidity, functional

impairment and mortality. However, obtaining accurate anthropometric measurement is a skill, which requires special training. Standardizing methods help to ensure that the measurements will be correct and make comparisons possible. Getting accurate anthropometric techniques can be problematic due to their vulnerability to measurement errors and lack of reliability. Imprecision in measurement may occur due to intra- and inter-observer variability, which can arise from inadequate or improper training of personnel and also due to instrumental or technical errors. It can be especially problematic in large epidemiological/surveillance studies that require multiple observers. Choosing appropriate equipment and measurement protocols and providing regular training and standardization of data collectors are critical aspects to minimize these errors.

Challenges in measuring waist circumference

Though seemingly an easy procedure to perform, there is no universally accepted approach to the measurement of waist circumference. Waist circumference measurements can be affected by a myriad of factors such as an improperly positioned measuring tape, subject movement or changes in position, and differences in the tension applied to the measuring tape. Changes in any of these factors reduce both the validity and the reliability of the measurements. A study by Agrawal *et al.*⁽¹⁶⁾ showed that waist measurements made using several methods can vary as much as 5.5 cm. A major challenge in measuring the waist is that it lacks firm landmarks. The umbilicus is not a reliable landmark because its shape can vary on the basis of changes in subcutaneous adipose tissue, skin laxity, and subject posture. The identification of the iliac crest, which is one of the acceptable landmarks has the limitation that, it is rounded and the soft tissue covering the iliac crest can move over the bone, making it a somewhat subjective landmark and difficult to pinpoint precisely from one time to the next and from person to person. Different studies use different sites to measure the waist. Finally, the phase of respiration i.e., inspiration or expiration can markedly influence waist measurement.

Challenges in measuring blood pressure

Blood pressure determination continues to be one of the most important measurements but unfortunately it is one of the most inaccurately performed. There are two main reasons for this: (1) the inherent variability of blood pressure and (2) inaccuracies in the methods, some of which are avoidable. It is widely accepted that diastolic pressure measured while sitting is higher than when measured supine (by approximately 5 mm Hg).⁽¹⁷⁾ If the back is not supported (as when the subject is seated on an examination table as opposed to a chair), the diastolic pressure may be increased by 6 mm Hg.⁽¹⁸⁾ Crossing the legs may raise systolic pressure by 2 to 8 mm

Hg.⁽¹⁹⁾ If the arm is held up by the subject (as opposed to being supported by the observer), the isometric exercise will raise the pressure.⁽²⁰⁾ There are also a number of other factors which can cause significant deviations in measured blood pressure, which include room temperature, exercise, alcohol or nicotine consumption, muscle tension, bladder distension, talking, and background noise. Use of improper equipment is a major issue. If mercury sphygmomanometers are used, use of the Korotkoff 4th sound (“muffling”) versus 5th sound (“disappearance”) can affect the readings. Use of electronic machines can help eliminate this error but accuracy of the machines remains an issue. Calibration of machines and proper training can help improve the accuracy and obtain reliable readings.

Challenges in assessing tobacco consumption

In most of the NCD risk factor surveillance studies, tobacco use is assessed based on subject’s self-reported information, which is used to assess the detrimental health effects of smoking. Self reporting, however, can be unreliable if the subject is under pressure because of social or medical disapproval and hence he or she tends to provide socially desirable responses. Furthermore, the quantity of smoke actually inhaled and absorbed varies according to the manner of smoking. Most of the smoking models from developed countries are based on cigarette use, whereas the forms of tobacco consumption in developing countries like India include beedis, cigars, cigarettes, cheroots, cigarillos, chutta, dhumti, pipe, chilum and hukka, among others. Chewing tobacco is also very popular in a mixture such as pan masala or pan chewed with salted lime, chewed with aracca nut or as snuff, khaini, mishri, gutka, etc. Studies evaluating the relationship between biochemical measurements and self-reported cigarette smoking among known smokers indicate that serum levels of nicotine and of its principal metabolite cotinine, plateau above 20 cigarettes per day.^(21,22) Surveillance studies that rely on self-reported smoking status are subject to underestimation of smoking prevalence. Thus increased emphasis has been placed on measuring exposure through the use of biological markers (e.g.: urinary cotinine levels) to provide more accurate estimates of smoking status.

Challenges in assessing diet

Despite many advances in dietary assessment methodologies in the past two decades, it remains a major challenge in epidemiologic studies to accurately quantify dietary intake in general population. The accuracy of the dietary intake data is dependent on the subject’s memory. A skilled interviewer should elicit information in a manner designed to put the participant at ease and to facilitate his or her ability to recall their dietary intake. Collecting a brief history of the previous day’s activities prior to beginning to ask questions about

food intake may improve the subjects' recall potential and set the stage for later questions. Other challenges include regional variations in dietary habits and cooking methods, which makes taking a dietary history extremely difficult.

Challenges in assessing physical activity

Accurate quantification of physical activity remains a major challenge in epidemiological studies. Physical activity is a complex human behavior with large day-to-day variations. Measures of physical activity are prone to errors from day-to-day variations and inaccurate memory recall. The type, intensity, frequency, and duration of physical activity can exert independent effects on health outcomes. Structured exercise or sports participation is relatively easy to assess by standardized questionnaires. However, physical activities of light to moderate intensity, which are often incorporated into daily routines (e.g., transportation, occupation, and household chores), are more difficult to measure. Measurement of physical activity using objective methods, such as activity monitors, double-labeled water/indirect calorimetry, pedometers, and heart rate monitors, which are ideal to measure physical activity are not feasible in large epidemiological or surveillance studies.

Physical activity questionnaires are commonly used in NCD risk factor surveillance studies because they are practical, inexpensive, and put less burden on participants. These questionnaires are designed to elicit information on multiple dimensions of physical activities, including type, frequency, duration and intensity. Self reporting of such complex behavior as physical activity through a questionnaire is a cognitive challenge for many people, especially if the subjects are children or elderly. In general, subjects tend to over-report physical activity and under-report sedentary behavior, which are influenced by cultural and social desirability factors. In rural areas, it becomes an even greater challenge.

It is noteworthy that none of the physical activity tools used in an epidemiological setup can capture all the dimensions of physical activity. One obvious reason is that most physical activity reported by the general population is of light to moderate intensity, a difficult category to capture with any method. Thus measurement error is inevitable in physical activity assessments.

General Challenges in Obtaining Accurate Data on NCDs

Other than the two surveillance studies on NCDs (WHO STEPS and IDSP), there have been a few scattered studies conducted in different parts of the country. To date, there has been no national study, which has looked at

the prevalence of NCDs in India as a whole, covering all the states of the country and the data on NCDs are often not integrated into national health information systems. Improving country-level surveillance and monitoring must be a top priority in the fight against NCDs. In low-resource settings with limited capacity, viable and sustainable systems can be simple and yet produce valuable and meaningful data. One of the major challenges in countries like India is the low levels of awareness about NCDs. Moreover, India has 22 official languages and hundreds of dialects. Thus to do a nationwide surveillance study, translation of questions into multiple languages is a must. This itself is a challenge given the enormous task of translating and back translating without changing the meaning.

Challenges in Field Operations in NCD Risk Factor Surveillance

Executing NCD risk factor surveillance studies involves several challenges. Research involving field operations, involve people who are healthy but presumed to be at risk; data collection takes place "in the field," usually among non-institutionalized people in the general population. Since the subjects are disease-free and the purpose is to prevent diseases that may occur with relatively low frequency, field trials are often logistically complicated and expensive endeavors. Though these studies aim to provide accurate measures of disease occurrence (or other outcomes), there are many possibilities for errors in measurement. Epidemiologists devote much attention to minimizing errors and assessing the impact of errors that cannot be eliminated. Success in surveillance studies depends on anticipating the challenges and effective management of them. Some of the common challenges in field operations [Table 1] are discussed below:

Contacting subjects

Availability of the study subjects is most important aspect of field operation, more so in urban areas. In urban areas, contacting the working population takes several visits to their households. Weekends, public holidays, late evenings often work better for these subjects. Non-availability of the subjects is more common during

Table 1: Challenges in executing noncommunicable disease risk factor surveillance in India

Challenges in field operations

Contacting subjects
Convincing subjects
Creating rapport
Tracking subjects
Climatic conditions
Recall ability
Interviewer ability
Conducive surroundings

festival periods and summer vacation days. Informing the subjects in advance and seeking their convenient date for appointment helps to overcome this problem.

Convincing subjects

Once contacts are made, convincing the subjects to participate in the study is crucial. The study protocol needs to be explained to them and only after obtaining their consent can they be included in the study. In case of diabetes screening, convincing the subjects for collecting blood samples is even more challenging. For refusals, multiple visits need to be made to convince them to participate in the study. Emphasizing the importance of the subject's contribution to the research and stressing the need for obtaining accurate information for the state or country often helps to get better response.

Creating rapport

The key for field operation is to build trust and rapport with the subjects. In the case of long-term surveillance studies, creating good rapport and maintaining good relations is imperative for success.

Tracking subjects

Surveillance studies are used to find out the changes in individual or group behavior over an extended period of time by repeatedly monitoring the same subjects or same cohort. While conducting these studies, there are risks of losing some of the subjects from participating for any number of reasons. Tackling this challenge and improving retention of subjects is essential. Keeping track of the subject's movement to other places is hence important to improve response rates.

Climatic conditions

Climatic conditions (monsoons, hot weather) often play an important role in determining the subject recruitment rate. However, this can be overcome by proper planning.

Recall ability

Data collection from subjects depends mainly on their recall ability. In case of dietary recall, one's ability to recall food intake is associated with a number of factors including age of the participant, gender, intelligence, mood, attention, and consistency of eating pattern. However, memory limitations can be minimized by using well-trained interviewers who are skilled in the art of asking questions that help subjects remember the events.

Interviewer ability

The interviewer's ability to ask questions in a non-judgmental manner, to maintain a neutral attitude toward all responses, to use open-ended questions in probing for descriptive data, and to avoid asking questions in a manner that might influence the subject's

responses are important factors in obtaining complete and accurate information.

Conducive surroundings

Providing relaxed and conducive surroundings gives the subject a chance to respond to the questions appropriately.

Conclusions

NCD risk factor surveillance is quite challenging, as the NCDs are chronic diseases and have prolonged exposure to risk factors and clinical manifestations. NCD risk factor surveillance system would help in assessing its prevalence, establishing its risk factors, monitoring the trends over time, policy planning and help prioritize the allocation of health resources. However, there are several challenges involved in executing these surveillance studies in developing country like India, which were discussed in this article. Worldwide attention has been driven by NCDs due to its huge burden posed on the economy globally. The United Nations' High-Level Meeting on NCDs held in September 2011 addressed the prevention and control of NCDs worldwide, with a particular focus on developmental and other challenges and social and economic impacts, particularly for developing countries. This is an excellent opportunity to create a sustained global movement against premature death and preventable morbidity and disability from NCDs.

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