

RESEARCH ARTICLE

Developing a health registry for Coastal Population: Protocol of the Valiyathura Population Based Health Registry in Kerala, the southern coast of India

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Published online on 2nd May 2016

ABSTRACT

Introduction: Health registries are valuable resources for epidemiology. It allows exploring large population level data as new hypotheses arise and test for multiple causal factors. More innovative ideas need to be integrated with current data collection designs to make registries economically feasible. Most Low and middle income countries have rudimentary surveillance and registration systems. Even where these exist, their robustness is doubtful and does not have adequate coverage to substantiate its validity. However, the potential for research and policy making is enormous when viewing population registries. Going by this view, Valiyathura Population Based Health Registry (VPBHR) focuses on coastal population from Valiyathura coastal ward in Thiruvananthapuram, Kerala.

Design: The registry is designed as a longitudinal survey to collect ongoing information on the health status, health behaviors and socio-economic status that influence the health of the people. The baseline survey data had collected information on hypertension and diabetes mellitus among population 25 years of age and above and the risk behaviours for life style diseases among other details.

Ethics and dissemination: Institutional Ethics Committee of Global Institute of Public Health at the Ananthapuri Hospitals and Research Institute (AHRI) approved this study. Informed consent was taken from all participants before collecting the data. The findings from the study will be published in peer reviewed journals.

Key Words: Health Registry, Public health Surveillance, Coastal community, Incidence of hypertension, Incidence of diabetes, Prevention of cardiovascular disease

Cite this article as: Shaffi M, Anand TN, Pillai M, Rajendrakumar AL, Sreemathy LS, Nayar KR, et al. Developing a health registry for Coastal Population: Protocol of the Valiyathura Population Based Health Registry in Kerala, the southern coast of India. Journal of Health Systems. 2016 May 2;2(1):11–5.

Background

Health registries are valuable resources for epidemiology. It allows exploring large population level data as new hypotheses arise and test for multiple causal factors. Wide variation exists in definition of health registries but generally they are

database for storing information and particularly for health information at a population level.¹ This differentiates population registries from more individualized electronic health records.² Another difference is that the data from population registry is intended to provide information on pre designated outcomes rather than simply analysing data and finding outcomes.³

Health registries aids in observing high risk groups, disease trends and evaluating prevention strategies by following them over a time period.⁴ Linking small registries to create a large multi centric database is another proposed alternative to creating an expensive single large database.⁵ Even though the benefits of health registries are well documented,⁶ the challenges are huge.⁷ The major hindrances to maintaining health registry are standardization, maintenance of database and absence of related

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workforce.⁸

Most low and middle income countries have rudimentary surveillance and registration systems.⁹ Even in developed nations their robustness is doubtful and does not have adequate coverage to substantiate its validity.¹⁰ Thus linking databases to obtain pooled estimates with high study power still remains elusive in these countries.³ However, the potential for nested research and policy making is enormous when viewing population registries.¹¹ Normally registries may contain single point or longitudinal data¹² while the latter is expensive content the utility is manifold. Going by this view, Valiyathura Population Based Health Registry (VPBHR) is designed as a longitudinal survey to collect ongoing information on the health status, health behaviours and socio-economic status that influence the health of the people. This health registry focus on population from Valiyathura coast in Thiruvananthapuram, Kerala.

Objectives

The Primary objectives of the registry are

1. To estimate the prevalence of hypertension and diabetes mellitus among population 25 years or above.
2. To measure the incidence of hypertension and diabetes among population above the age of 25 and the causative factors of the same
3. To understand the adherence to treatment for hypertension and diabetes including life style modifications and to document its impact on prevention of complications.

Secondary objectives include

1. To explore the prevalence and pattern of tobacco and alcohol use.
2. To assess the level of awareness and attitude towards hypertension and diabetes in the community, especially with regards to the complications of the diseases
3. To document the prevalence of cardiovascular diseases and cancers in the population
4. To examine and document the reported causes of death using verbal autopsy method, for the reported deaths during baseline

Rationale

Studies have reported high prevalence of lifestyle diseases in Kerala.^{13,14} High levels of urbanization and related transitions are driving this epidemic in the state. Kerala has 550 km coast along the Arabian Sea.¹⁵ However, details of the ongoing epidemiological transition are not available for subgroups beyond descriptive statistics, especially the tribal population¹⁶ and the coastal fishermen community.¹⁷ To this end, this registry was developed to examine disease burden and related risk factors in the vulnerable coastal population.

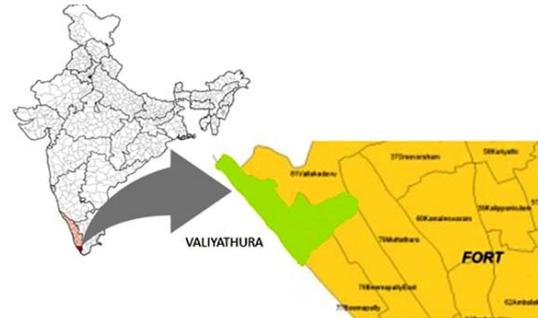


Figure 1. Map of the health registry field area

Study design and setting

Valiyathura is a coastal ward in Trivandrum district with more than 80% adult population involved in fishing and related jobs, though many households depend also on the income of the non-residents working in middle east countries, and then there are small merchants and those who depend on tourism industry for daily living. Even though it is part of the City, the socioeconomic background of the population is still lower.¹⁰ The geographical location of Valiyathura ward is shown in **figure 1**.

According to a household survey conducted by Kerala Institute for Local Administration (KILA) in 2010 the total population of the ward was around 4847 with 48.5% females. The household size is larger among the fisher households with 5.4 members per household as against 4.4 among non – fishery households. Fishery households are predominantly from Christian faith, followed by Islam and Hinduism. The overall sex ratio was favorable at 1032 in the non – fishery households against an unfavorable 931 in the fishery households.¹⁰

Valiyathura Population Based Health Registry (VPBHR) is designed as a longitudinal survey to collect ongoing information on the health status, health behaviors and socio-economic status that influence the health of the people. The baseline survey had collected information on hypertension, diabetes mellitus and the risk behaviors for life style diseases among population of age 25 years and above. A flowchart of the study plan is given in **figure 2**.

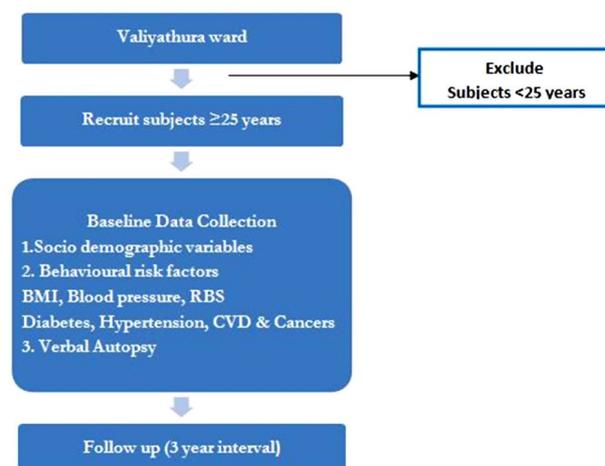


Figure 2. Schematic representation of the study protocol

Table 1. Variables in the baseline questionnaire

Socio Demographic Profile	
Age	Cooking Fuel
Gender	Electricity Connection
Type of housing	Education
Anthropometric Measurements	
Height	
Weight	
Blood sugar measurements (RBS)	
Blood Pressure (BP)	
Medical History	
Diabetes	Thyroid disorders
Hypertension	Tuberculosis
Heart diseases	Kidney disease
Stroke	Cancer & site
Other diseases	Injury & type
Risk behavior	
Tobacco consumption	Type of Tobacco
Alcohol consumption	Alcohol intake pattern
Verbal Autopsy (for those who died in last five years in the household)	
Age	Primary cause of death and other causes
Sex	Co morbidities
Medical History	

VPBHR is a key component of the Coastal area Comprehensive Health Project (CCHP) in Trivandrum coast of Kerala state, India. CCHP was initiated as a unique public private partnership model between Government of Kerala represented by the Department of Health and the Global Institute of Public Health in the year 2013 and was aimed to understand the specific health issues of the coastal population in Kerala and to plan scientific, evidence based interventions suiting to the socioeconomic conditions of the predominantly fishing community living in the coast. CCHP had a key community component, aimed to involve the community members and key community organizations in health and related issue. A series of meetings were conducted in the period December 2013- March 2014, where in the research team, staffs from the Valiyathura primary Health Centre catering to the population and the community members sat together and planned the project. Aims of the CCHP project including the VPBHR were shared with the community members including the people's representative in the corporation, religious heads, office bearers of the community organizations and self-help groups. Junior Public Health Nurses (JPHN), Accredited Social Health Activists (ASHA), Anganwadi (pre-school) workers (AWW) supported the research team in mapping the area and dividing the total study area into multiple sub-units based on streets.

Baseline

The baseline household survey collected data on socio demographic variables, housing, cooking fuel and other socio economic variables. Further, data on risk behaviors and medical history of respondents 25 years and above were taken. For deaths reported in the households within last 5 years, verbal autopsy on causes of death were also collected from the closest relative. The variables in the questionnaire are given in the table below (**table 1**).

Study eligibility criteria:

All the residents of Valiyathura ward with age 25 years or above from each household for the study, available on the day of field visit.

Field staff and data collection for baseline:

The public health field staffs of Primary Health Centre, Valiyathura, BSc (nursing) students of Ananthapuri College of nursing, Anganwadi workers, ASHA workers, Residents association representatives and volunteers from the community were involved in the data collection. The data was recorded by the BSc (nursing) students of Ananthapuri College of nursing, with the support of Anganwadi workers ASHA workers, street resident's association representatives and volunteers from the community as in baseline survey. The research team from Global Institute of Public Health supervised the entire research process. Nursing students were divided into 20 teams and each team visited the area for 6 consecutive days. Data was obtained from all households providing consent for the study.

Glucometers and electronic digital blood pressure monitors were used to measure physiological parameters. Anthropometric measurements were collected to explore association with disease outcomes. Special training was given to non-medically trained staff for using glucometers, electronic blood pressure monitors and for taking anthro-

Table 2. Prevalence of major diseases in the cohort

Risk factor / Disease condition	Prevalence (N=2793)
Current tobacco use	16.3%
Current alcohol use	16.7%
Self reported hypertension	25.9%
Self reported diabetes	20.4%
Cardiac disorders	5.5%
Stroke	1.0%
Renal Disorders	1.4%
Thyroid disorders	5.5%
Cancer	0.7%
Injury	1.0%
Tuberculosis	0.6%

pometric measurements. Self reported medical history, economic status and risk behaviors (tobacco, alcohol) was collected using structured questionnaire through face to face interview. Verbal autopsy regarding those deceased in last five years was done.

Reported burden of diseases in baseline survey

The baseline survey gathered data from 2793 individuals from 1603 households. From the reported burden of different chronic conditions and injuries in this baseline survey, a snap shot of the estimate of the disease or risk factor burden is given in **Table 2**.

Follow-up plan

The study is envisaged as a longitudinal study with follow up of specific cohorts identified from the baseline, at specific intervals. The incidence of diabetes (based on Fasting Blood Sugar values) and hypertension will be measured every three years, as well as prevalence and changes in pattern of tobacco and alcohol use. A sub-set will be studied to assess the level of awareness and attitude towards hypertension and diabetes in the community, especially with regards to the complications of the diseases. The prevalence of cardiovascular diseases and cancers in the population will be repeatedly measured every five years

The data collection will be supervised by the research team from Global Institute of Public Health and will be done by BSc (nursing) students of Ananthapuri College of nursing, with the support of Anganwadi workers ASHA workers, street resident's association representatives and volunteers form the community as in baseline survey

Appropriate interventions in terms of primary and secondary prevention for cardiovascular diseases will be undertaken as informed by the data

Strengths and Limitations

The VPBHR registry provides a cost effective and community centered approach to estimate disease progression and its burden in a vulnerable group. Similar health registry however on a much higher population level was attempted successfully previously in the state.¹⁸ This study may provide clues to the occurrence and rates of chronic diseases and risk factors in currently rapidly urbanizing but previously deprived population. We also hope to extrapolate the findings to coastal population sharing similar characteristics elsewhere in the state.

The main strengths is the selection of a large group of subjects with younger age groups, though the results may only be generalizable to the coastal population The community involvement in development of such a registry is also uncommon. One of the main limitations is that we measured only the basic variables at the baseline. We hope

to resolve this and improve the range of variables during the follow-up measurements. A long follow-up interval is also a limitation, especially with incidence measurements of diabetes and hypertension; which was mainly due to funding constraints. We also report that we could not gather data on the people who have migrated to other places.

Ethics Approval:

Institutional Ethics Committee of Global Institute of Public Health at the Ananthapuri Hospitals and Research Institute (AHRI) approved this study. Informed consent was taken from all participants before collecting the data and were informed of future use of data for analysis and follow up plan.

Quality Control

All the data collectors were trained in physical measurements and using the questionnaires. All standard guidelines were followed for measuring height, weight, blood pressure and blood sugar measurements. Instruments were calibrated before measurement. The data was again checked at the backend after data collection. The disease status was reconfirmed by the supervisor by contacting the respective households. Later, the data was transferred from paper questionnaire into an Epidata platform. Specific skips and ranges were incorporated in the data platform to ensure quality. The same quality checks will be ensured in follow up.

Data Analysis

All analyses will be performed with R version 3.2 and related epidemiological packages. Basic frequency analysis will be done initially followed by bivariate and multivariate methods. Chi-square tests with Odds ratios will be used for bivariate associations. Multivariate analysis will be performed to obtain adjusted estimates and prediction. Continuous outcomes analysis will involve multiple linear regression and multiple logistic regression for binary outcomes respectively. In addition to the prevalence of diseases we will also explore uncontrolled diabetes and hypertension among the self reported subjects. For baseline, the RBS cutoff will be based on the mayo clinic guidelines and JNC-8 report will be used to categorize hypertension. The BMI cutoffs will be decided from the CDC guidelines. Chi-square test for trend and ordinal logistic regression will be performed for ordered outcomes variables. A p value of < 0.05 shall be considered as statistically significant.

Discussion

This paper describes the development of a population based health registry to quantify the disease burden and related risk factors in the coastal Kerala setting. Our

registry is in line with previous attempts to develop community centered database for public health research. Notwithstanding the limitations mentioned above, a health registry of this kind will provide reliable data in the future to target interventions and develop relevant policy. Additionally, the registry will help to track the progress of disease overtime and allow researchers to explore risk factor associations with the disease end points.

Conflict of Interest: None declared

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