

Research Article

Missing stillbirth data: a hospital based study

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Received: 16 August 2016

Accepted: 10 September 2016

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ABSTRACT

Background: Stillbirths has remained a neglected issue, invisible in policies and programmes, underfinanced and in urgent need of attention. In India inadequacy has been observed in monitoring of the time and cause of death of unborn infants. So the present study attempts to assess the problem of underreporting and completeness of the information of data in stillbirth registry in a tertiary care hospital in Northeast India and analyse the cause behind it.

Methods: The study was carried out from January 2016 to June 2016. Case sheets related with stillbirth born during the period of study were retrieved, detail information regarding address of the mother, her age, gestational age, gravida and parity, medical and obstetrical condition leading to stillbirth, gestational age, weight, sex and condition of the fetus at the time of birth (macerated or fresh) were noted. The information was compared with the data entered in stillbirth registry. Process of entry of stillbirth data was observed and interns and PGs who entered the data were interviewed using a semi structured proforma.

Results: Stillbirth rate for the hospital was 27.95/1000 births. All information regarding stillbirth except information regarding condition of the fetus (macerated vs. fresh) were present in case sheet, but only 59.64% of stillbirth had mention of their sex and weight in the register.

Conclusions: Lack of training, hectic activity in labour rooms and absence of dedicated staff results in incomplete entry of stillbirth data in the register.

Keywords: Missing, Stillbirth, Data

INTRODUCTION

Stillbirths have been invisible in the World Health Organization (WHO) reports on the global burden of disease and in the United Nations (UN) millennium development goals and targets. According to the most recent WHO reports on perinatal mortality, 90 countries worldwide lacked any kind of data on stillbirths. Improvements in basic registrations of stillbirths are both possible and urgently needed.

Being counted is essential. Systematic and reliable registration of stillbirths is crucial to any health care program planning in this field. Accurately counting stillbirths is the first step towards any improvement.¹ A fetal death is defined as “death prior to the complete

expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy; the death is indicated by the fact that after such separation the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles” without specification of the duration of pregnancy and ICD classifies late fetal deaths as one born with birth weight greater than 1000 gms or after 28 weeks of pregnancy.^{2,3}

For purposes of international comparison late fetal deaths are considered as stillbirths. “stillbirth” is not a technical term.³ Stillbirths has remained a neglected issue, invisible in policies and programmes, underfinanced and in urgent need of attention.⁴ It has been underreported and has been

accounted only to the extent of 2% in vital registration. No data source recording stillbirths even in country like Australia were 100% accurate and reliable. However, the administrative datasets has been better than the self-reporting data.⁵ Birth registries across the world has observed missing data on birth weight, gestational age, or stillbirths.⁶⁻⁸

In India inadequacy has been observed in monitoring of the time and cause of death of unborn infants.⁹ Government of India has planned to reduce the SBR to <10 by 2030, and to achieve the target, it has given priority to establish a sound surveillance system for tracking stillbirths.¹⁰ So the present study attempts to assess the problem of missing data in stillbirth registry in a tertiary care hospital in Northeast India and analyse the cause behind it.

METHODS

The study was carried out in a tertiary care hospital from northeast India, from January 2016 to June 2016. Stillbirth was defined as the late fetal death occurring after 28th week of gestation and weighing more than 1000gm. Ethical clearance was taken from the institutional ethical committee prior to the initiation of the study.

All case sheets were retrieved from the department of records and were examined for detail information regarding address of the mother, her age, gestational age, gravida and parity, medical and obstetrical condition leading to stillbirth, weight, sex and condition of the fetus at the time of birth (macerated or fresh). The data was compared with the data available in the stillbirth register. Process of entry in the stillbirth register was observed without disturbing the normal labour room activities. About 20 numbers of health care providers comprising of interns, residents, and registrar of O&G were interviewed using a semi-structured questionnaire which included variables such as what is stillbirth?, numbers of stillbirths occurring daily, how the records of stillbirth are entered in the register?, did they get any formal training for entry of the stillbirth records?, if not how did they learn the art of the entry of records?. Health providers were also asked to explain the missing information in stillbirth register

Stillbirth rate (SBR) of the hospital was calculated by dividing the total numbers of stillbirths registered to that of the total birth during the period per 1000 live birth. The percentage of missing data was calculated by dividing the total number of missing data with that of the total numbers by stillbirths.

RESULTS

Total 4078 numbers of live births were recorded during the period of study. Total number of still births recorded in the stillbirth registry was 114. Stillbirth rate for the

hospital was 27.95/1000 births. All the case sheets of the mothers with stillbirths contained detailed findings of the mothers including the address, the time of delivery, fetal information, timing since fetal movement was not felt, adverse obstetric conditions leading to fetal death, Stillbirth classification criteria such as term vs preterm, cause of death, weight and sex of fetus were clearly mentioned in the case sheets but macerated vs. fresh was not mentioned.

All stillbirths were counted in the stillbirth register but only 59.64% of stillbirths had mention of their sex and weight. Reporting criteria for stillbirth classification such as term vs. preterm, macerated vs. fresh and cause of the death were not mentioned for any of the stillbirths in register.

The entries in the stillbirth registry were usually done by interns and PGs. All the interns and PGs knew the definition of stillbirth, and agreed to the importance of the data on stillbirths but complained of tremendous workload due to large numbers of deliveries taking place in the hospital. Patient care was considered more important than double entry of data (in case sheet and stillbirth register). None of the interns or PGs were explained or trained in data entry process. They copied the art from the previous entries.

DISCUSSION

The estimated average global SBR in 2015 was 18.4 per 1000 births. Highest SBR was reported from Pakistan (43.1/1000 of total births).¹¹ The stillbirth rate for this hospital was at 27.95/1000 births which is slightly higher than the all India rate of 22/1000 live birth.¹⁰

Government of India has planned to reduce the SBR to <10 by 2030, and to achieve this target, it has given priority to establish a sound surveillance system for tracking stillbirths.¹⁰

During bottle neck analysis it was observed that existing reporting platforms neither were covering the entire components nor the reports were being used for planning or midcourse correction. It was also observed that the reports were not being validated.¹⁰ No data source on stillbirths even in developed country like Australia is 100% accurate and reliable¹² resulting in missing data. Birth registries across the world has observed missing data on birth weight, gestational age, or stillbirths.⁶⁻⁸

In the present study, the case sheets had all information on reporting criteria for stillbirth except condition of the fetus (macerated vs. fresh) at the time of birth. All stillbirths were properly counted in the stillbirth register but only 59.64% of stillbirths had mention of their sex and weight in the register.

Cause of death was not mentioned in the register for any of the stillbirths. In India inadequacy has been observed

in monitoring of the time and cause of death of unborn infants.⁹ In a study of records of Government hospitals of Rajasthan, India, it was noted that for reporting stillbirths, reporting criteria such as uniform clinical classification of stillbirths, term vs preterm, intrapartum vs antepartum, macerated vs fresh; with or without congenital anomalies were absent in the recording system.¹³

According to Kayode et al most of the errors in the data were committed during collection of the primary data; indicating the necessity of double check procedures.¹⁴ In community setting and in data collection by untrained personal, birth weight of stillbirths has been difficult to collect, often because of cultural barriers.¹⁵

In a study in west Timor's largest referral hospital fifty-two of the 153 stillbirths (34%) had no maternal or obstetric details, in 62.7% of stillbirths cause of death was recorded as unknown, and condition at the time of birth (i.e fresh or macerated) was not documented.⁵

The definition recommended by WHO for international comparison for stillbirth is "a baby born with no signs of life at or after 28 weeks' gestation or birth weight >1000gm".¹⁶ Failure to adhere to WHO definitions hampers stillbirth epidemiology.¹

In the present study only 59.64% of stillbirth had data on birth weight and sex in stillbirth register, data on rest of the stillbirth could be included in the study just because the data was available in the case sheet. Data on macerated vs. fresh was not available both on case sheet and the register for any of the stillbirth. Data on the stillbirth register is transmitted onwards for inclusion in regional and national registries. Missing data on weight and sex of the stillbirth affects the SBR and stillbirth classification. Hence the missing data must have had adverse effect on the analysis of the stillbirth data.

As the vast majority of stillbirths are preventable, being counted is essential. Accurately counting will provide an opportunity to set specific goals, the first step towards any improvement.¹

In a study on underreporting of pertussis cases it was observed that diffused responsibility of reporting among different personnel and absence of proper definition for the disease to be reported, manual processes of data entry combined with knowledge deficits, contribute to problems with underreporting.¹⁷

For the birth attendant, with first-hand knowledge of the adverse event, there may exist barriers to reporting. In most communities and for many reasons, health care professionals traditionally tend to underreport adverse events and outcomes, irrespective of whether they are objectively to blame for the event. Some of the criteria for collection and reporting of quality stillbirth data were described as dedicated and motivated staff, training in registration and classification, feedback and other

incentives for motivation, local adaptations of a sustainable system for registering and reporting.¹ In a study for quantifying the validity of routine neonatal healthcare data in the greater Accra region, Ghana, the main cause of the errors in the data were committed during collation of the primary data; indicating that the introduction of double check procedures reduces the occurrence of errors in the database to a negligible level. This procedure is an analogue of double data entry.¹⁴

The main causes of poor registration in India are said to be: involvement of multiple line departments, lack of attention and priority for registration, lack of system for preparation and submission of statistical returns and lack of demand for birth and death certificate in schools and other places. Lack of awareness is also one of the reasons for low coverage of civil registration system (CRS).¹⁸

Hospital information system, in most developing countries remain fragmented and weak due to underinvestment in data collection, processing and analysis. The most common issues affecting quality of data from administrative data system are 1. inadequate coverage, 2. undercounting 3. manual and centralized processing 4. lack of skilled staff to undertake data processing, coding and classification 5. lack of quality control mechanism. One of the reason for poor quality of records is incomplete filling of the prescribed form and medical practitioners illegible and incomplete reporting. Poor quality control mechanism at the primary data collection level resulting in data error that is carried forwards. Absence of regular training programme, lack of specialized well trained staff contribute in error in data collection and transmission to next level.¹⁹

In the present study the data on stillbirth was entered by interns and junior residents who were busy in multiple activities in the hectic environment of the labour rooms, the duty schedule of the interns and residents kept them shifting from labour rooms to OPDs, post OP wards and minor OTs.

On being interviewed they agreed that none of them have received any training on data entry and they have learned it from their seniors. The missing data in the register may have been caused due to lack of dedicated staff and lack of training. Cross checking with case sheet would have reduced the chances of error.

CONCLUSION

Training the interns and JRs, motivating them, supervising the entered data on regular basis and ensuring the double checks can reduce the errors in the data register. Employing a permanent person who can be trained accordingly for entering data in register and to ensure cross check each and every information sought by the regional and national registries, will reduce the errors in data entry to minimum.

ACKNOWLEDGEMENTS

Authors would like to thank the Medical Record Department and Dr. Siddharth Hazarika, JRs who helped me in collection and analysis of data from the case sheets.

Funding: Indian Council of Medical Research, New Delhi, India

Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Kusre G, Baruah J. Missing stillbirth data: a hospital based study. *Int J Community Med Public Health* 2016;3:2949-52.