REVIEW OF AVAILABILITY, REGISTRATION AND QUALITY OF HOSPITAL BASED DEATH STATISTICS AND DETERMINING MORTALITY PATTERNS BY CAUSE OF DEATH

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Abstract:
More than half of the world’s population are born and die without leaving a trace in any legal record or official statistics. At present, demand for reliable, comprehensive and timely mortality statistics is rising globally as they provide a snapshot of current health problems, suggest persistent patterns of risk in specific communities, and show trends in specific causes of death over time. Furthermore, because mortality data allow us to identify leading causes of premature death, within the realm of public health, these are often used as a cornerstone in formulating health plans and policies to prevent or reduce premature mortality and to track progress towards SDGs. Civil Registration and Vital Statistics (CRVS) system is the gold standard for generating reliable, continuous and comprehensive mortality statistics but at present, the system is weak in Pakistan and it does not produce disaggregated vital statistics reports from civil registration data. Information about cause of death from health facility records provides another approach to the generation of cause-of-death statistics.

A cross sectional study was launched to identify current practice of death and cause of death recording/registration at hospitals, availability of mortality data supported by ICD coding, to analyze trends on cause of death, arrangements or readiness available in terms of physical, human / training, IT Support, capacity and other resources in Tertiary and Secondary Health facilities of Punjab. A purposive sampling technique was used for selection of data collection sites (health facilities). However, the focus was on major 20 facilities (including both Tertiary care and DHQ hospitals) of the province. Standardized structured questionnaires were used for data collection.

The findings of the study highlighted that no standardized data format (with ICD-Coding) is available. So, data on causes of death was collected and analyzed for total number of deaths reported indoor and by leading cause/disease, age group and gender (health facility wise). Major causes of neonatal deaths has been evaluated and a comparison has been made for reported number of deaths and death rate. The report has summarized key mortality related indicators and describes the limitations and gaps of hospital-based data. Conclusion has been drawn that as an important and major source of mortality data, there is need to optimize the functioning of hospital’s statistical departments by introducing standard formats, ICD mortality coding and capacity building of the staff to improve the availability and quality of mortality statistics.

Keywords: Civil Registration & Vital Statistics, Cause of death, ICD Coding
Introduction:
Majority of the people in all parts of the world are born and die without leaving a trace in any legal record or official statistics. At present, demand for reliable, detailed and timely mortality statistics is rising globally to underpin public health priorities/decisions and to track progress towards national and international targets and goals such as Sustainable Development Goals (SDGs). Good quality and continuous mortality statistics are currently not available in many countries. In the majority of developing countries, death registration coverage is low or not existent, making it difficult to calculate most basic mortality indicators such as crude mortality rates from the routine civil registration system.

The situation is even more problematic when it comes to the quality of cause-of-death statistics. This type of information can usually be compiled either through the collection and coding of routine medical certification records from health facilities or through collecting information about community deaths through sampled collections methods using verbal autopsy. Up to 80 percent of deaths occur outside of health facilities in low- and middle-income countries. Only 81 of 194 countries can report high-quality or medium-quality data on deaths and causes of death depicting that critical mortality indicators, such as newborn, infant, child and maternal mortality and death rates due to HIV/AIDS, tuberculosis, and other diseases, are estimated from very limited information.

The cause of death data is vital for pinpointing the diseases and injuries that are cutting lives short and for planning preventive services to avoid premature mortality. It is also useful to inform governments regarding outbreaks of fatal disease and to look back in time to trace those who had contact with the victim. Unfortunately, there remain huge gaps in the availability and quality of these crucial data in many parts of the world. And this presents a major challenge to evidence based public policy. Only about 65% of all births are registered globally and only about one-third world/s 55 million annual deaths recorded through civil registration and up to 80 percent of deaths that occur outside of health facilities are not counted.

Ischemic heart disease, neonatal disorders, stroke, lower respiratory infections, diarrhea, road injuries, and chronic obstructive pulmonary disease (COPD) accounted for more than 1 million deaths each worldwide in 2017. Analyzing cause of death by category suggested that level of communicable, maternal, neonatal and nutritional diseases are among top category over a period of time has declined while non-communicable diseases are on rise. Total number of deaths from all causes, broken down by broad age categories over period of time has shown that majority of the deaths are occurring at the age of 70 and above (27.66%) in 2017 (23.92%) while there is decline in deaths under 5 in year 2017 as compared to 37.52% in 2002.

Mostly the government-based hospitals in Pakistan lack a systematic electronic hospital information system. Though there exists a standard health information system to support District Health authorities, some consistent/standard Health Information Systems is not available for public sector tertiary care hospitals. Similarly there are issues relating some proper data recording and reporting of community based deaths or use of verbal autopsy. Such information is usually available in district and tertiary hospitals in a disorganized,
fragmented and unanalyzed form. Hence, the improvement of death and cause of death information is an important component of National Plan for Strengthening of Civil Registration and Vital Statistics (CRVS). This subject is in fact considered as one of the core thematic areas of support for National CRVS promotion. Public health planning need to be based on reliable and timely data on the leading causes of death and disability. Similarly, determination of mortality causes and patterns are critical for the health care managers and planners. It seems reasonable to expect tertiary hospital-based (teaching) physicians to correctly identify patients’ underlying causes of death, since such hospitals are expected to have an established clinical protocols for monitoring disease progression. Physicians in hospitals could be the most authentic source for correctly ascertaining their patients’ cause of death and then communicating that to some central repository. For the community based deaths, procedures need to be developed for the use of verbal autopsy tools after training of community based health workforce or other staff.

2. Methodology:

A cross sectional study was conducted to identify current practice of death and cause of death recording and registration at hospital, availability of mortality data supported by ICD coding, to analyze trends on cause of death, arrangements or readiness in terms of physical, human training, IT Support, capacity and other resources in Tertiary and Secondary Health facilities of Punjab, Khyber Pakhtunkhwa (KP). For that purpose, literature review was conducted to know the exact situation in the country. International and National literature was reviewed to explore the existing situation regarding death registration practices, number of deaths, cause of deaths procedures and form enforced at respective organizations (i.e. hospitals). Further to match the national situation with global perspective along with use of ICD Mortality Coding practices in health sector and the impediments confronting it. Health profile of the country has been explored with existing system of health care service delivery. A purposive sampling technique was used for selection of data collection sites (health facilities). However, the focus was on major 20 Tertiary care and DHQ hospitals each of the Punjab and KPK province. While all public and private major hospitals were included in the study in ICT. Standardized structured questionnaires were used for data collection. Based on information received from hospitals, all data was entered in excel and then converted into SPSS program for further analysis. However, each hospital (from Punjab only) also provided DHIS Year Data (2018-2019) reports, which was analyzed and incorporated pertaining to death registration and causes of death indicators.

3. Results:

The findings of the study highlighted that no standardized data format (with ICD-Coding) is available. So, keeping in view this limitation, data on causes of death was collected and analyzed for total number of deaths reported indoor and by leading cause/disease, age group and gender (health facility wise). Major causes of neonatal deaths have been evaluated and a comparison has been made for reported number of deaths and death rate (Where available). The report has summarized key mortality related indicators and describes the limitations and gaps of hospital-based data. Comparison has made among Punjab and KP on major mortality indicators and leading causes of death. Conclusion has been drawn
that as an important and major source of mortality data, there is need to optimize the functioning of hospital’s statistical departments by introducing standard formats, ICD mortality coding and capacity building of the staff to improve the availability and quality of mortality statistics all over the country.

This assessment study revealed that majority of the hospitals visited during the study, do register and record the deaths which occurred in their hospitals during admission. Cause of death is usually determined jointly by the administrative and clinical department, where the deceased patients were admitted but final death registration is responsibility of the administrative department. As far as the completeness of death data among hospitals is concerned, it was observed that majority of hospitals in Punjab (12 among 20) came up with 70 percent response while 6 hospitals reported the level of completeness between 60 – 69 percent. Regarding registration coverage and including foreign residents, none of the hospitals have such option in their manual or computerized data system.

A comparison has been made among leading causes of death during 2019 in Punjab and KP. It has been revealed that there is entirely different scenario in both provinces regarding major deadly diseases. It is evident from the graph below that in KP, diarrhea/dysentery is the top most leading cause of death showing 1280 cases in mortality statistics. However, in case of Punjab, it is nowhere in list of top 15 diseases. In Punjab, majority of the deaths occurred due to Unusual Diseases (8320) followed by chronic liver diseases (5619). Cerebrovascular Stroke is reported among to five causes in case of both provinces (Fig-1).

Figure 1: Leading Causes of Deaths (Top Diseases), Reported in Hospital in two provinces
The study has suggested that there is good coverage and distribution of health infrastructure in the public sector in both provinces (Punjab, KP). However, there still exist a number of lacunas and gaps in the system in terms of mortality data availability, existence of data systems, data generation, development, consolidation, analysis and its use in the health sector. Punjab Health Care System, for example, comprises 43 Teaching Hospitals, 26 District Head Quarter Hospitals, 125 Tehsils Head Quarter Hospitals, 317 Rural Health Centers and 2,505 Basic Health Units. In spite of extensive network of health care facilities, health indicators of the province as a whole is below the desired level. Latest Punjab Annual Health Report (2017/2018) shows that maternal mortality ratio (MMR) (which indicates risk of death per pregnancy) is 227/1,000 live births. The main reasons of this high MMR is very low utilization of Family Planning services as the current CPR is reported to be 38.3%.

An estimated 14,000 Pakistani women die every year of pregnancy-related causes. Pakistan ranks 26th in the world for under-5 child mortality. Childhood mortality is highest in Punjab, where neonatal, infant, and under 5 mortality rates are 51, 73, and 85 deaths per 1,000 live births, respectively. It has been highlighted that there is no standardization of death registration and recording. Hospitals have developed their own formats which lack uniformity.

Moreover, International Classification of Disease (ICD) Coding is not in practice for documenting cause of death which is internationally standard system of mortality data recording. The study has depicted that majority of the hospitals are using mix system (both manual and electronic) for data aggregation and analysis. For data compilation and analysis, the staff responsible for compilation of data is usually not aware of its significance. There are no protocols for sharing of micro data to different users. Usually the mortality information from hospitals is collected and stored in District Health Information System (DHIS). Even though at present neither a standard certificate for cause of death is being used nor adequate labelling of cause is being practiced at health facilities, however the situation is not so unfortunate. Punjab Health Department has issued standard Death Slip to be used in all health facilities which will be implemented soon.

In Punjab, which is ahead in development, an android based CRVS Application has been developed by Punjab Policy and Strategic Planning Unit (PSPU) in Collaboration with Punjab Information Technology Board (PITB) to record deaths and cause of death based on ICD coding. Trainings has been imparted in Punjab and application is in phase of piloting in various hospitals. This mobile application may pilot in other provinces also. Technical Support Unit- CRVS under Ministry of Planning Development and Special Initiatives is continuously striving for strengthening of CRVS having Death certification, cause of death and ICD Mortality coding practices as important components.

Given the significance of mortality and morbidity statistics to health management and planning the capacities need to be built to address this issues as one of the health sector priority. Need exist to address this issue through a well thought off plan, where a more thorough assessment of hospital to hospital situation is made in terms of human and
physical resources and capacities desired to improve the situation.

Following are some of the key recommendations for the development of specific action plan and improvement of the current practice of data collection and reporting for the strengthening of Health Information System:

➢ Development of a comprehensive plan for improvement of hospital based morbidity and mortality statistics is desired on urgent basis.

➢ There is need to strengthen Civil Registration ad Vital Statistics System to produce continuous, real time and accurate mortality statistics along with cause of death Information. Indeed, the civil registration system relies on information provided by the health sector on numbers of deaths by age, sex and cause. This information should be part of the routine HMIS system and integrated into the District Health Information System (DHIS) to be shared with the civil registration authorities.

➢ In-depth review of health facilities/hospitals is required to understand the bottlenecks regarding its resources, infrastructure and capacities in terms of hospital statistics in general and mortality in particular.

➢ Death registration forms and certificates need to be standardized and uniform in all provinces with ICD enabled cause of death. Best practices should be considered in this regard (e.g. standardized Death Slip by CRVS Android App).

➢ District Health Information System (DHIS) needs to be upgraded with inclusion of ICD Coding and effective linkages should be established for data sharing

➢ There is dire need for immediate adaptation, piloting and implementation of ICD-10 coding for certifying cause of deaths on standard pattern. Android application (CRVS Application), an initiative by Policy and Strategic Planning Unit (PSPU) and Punjab Information Technology Board (PITB) may be adapted in all secondary and tertiary hospitals for death certification with cause of death.

➢ Capacity building of existing staff and trainings at all levels are needed to certify deaths with cause of death in an efficient and effective manner. Hospital MIS/Statistical Unit need to be revitalized to take the leading role in development, capacity building and system maintenance.

➢ Hospital death review committees be formulated or reactivated streamlined with clear terms of reference and roles. These should go for an in-depth review the causes of death coding on monthly basis. For improving data quality there is a need for a more interactive approach by sending a regular feedback to coders/UC secretaries after quality check and evaluations.

➢ Technology need to be incorporated and instead of manual or use of simple excel sheets for data aggregation and use, some demand driven hospital MIS software’s
(enabled for ICD Coding also) be developed and launched in government hospitals.

➢ There is a need to strengthen the analytical capacity of decision makers and data users. A culture of development of annual reports by the hospitals, be promoted by which causes of deaths be reviewed along with their distribution patterns in area, gender and age.

➢ There is dire need to change the overall culture regarding roles and responsibilities to certify deaths with cause of death and use of ICD Mortality Coding. Incentives and punishment theory may be implemented for behaviors change.

➢ Moreover, Curriculum need to be revised and ICD Mortality Coding should be included in the curriculum of medical graduates to develop a basic understanding.

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