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Perspective

Disease registry in the Armed Forces Medical Services: An Idea Whose Time Has Come

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The practice of medicine is shifting from one based on episodic care to one that is more focused on evidence-based standard of care management. This is particularly true for the management of most chronic diseases. As a clinician and a health administrator, it would be relevant to prioritize the top areas to track within a dependent patient population, identify the best clinical strategies to tackle chronic conditions, and also manage Human Resources (HR) and logistic requirements to ensure optimal delivery. To achieve the above at an organizational level would need detailed healthcare information to be available on all patients undergoing treatment at hospitals and for this information to be interlinked and be available for access and feedback. The optimal way to address this requirement would be to have a disease registry (DR) in place.

A DR would be defined as a surveillance system that collects and maintains structured records on the new cases of a specific disease or condition for a specified time period and population; a DR analyzes and interprets data of those with a common illness or adverse health condition.¹ These data can then be used to evaluate specific diseases, exposures, or outcomes for clinical, scientific, or policy formulation. General aims of a registry are assessment of disease burden due to a particular illness by quantification of morbidity, gauging geographical and temporal pattern; identification of risk factors and vulnerable population; evaluation of management and creating venue and interest for research.²

Registries are broadly of two types: hospital based and population based. Mostly, registries are hospital based, which collect data on all the patients with disease of interest, diagnosed and treated at that hospital.^{1,3} For example, a hospital-based joint replacement registry contains records

for all the patients who have undergone joint replacement surgery, including demography and outcomes, both short and long term. However, the registry would not include all the patients from the community, since some may go elsewhere for treatment. Population-based registries on the other hand collect records of people diagnosed with a specific disease who reside within a defined geographic region. In a population-based registry, data are collected on all the patients having a disease or having undergone a specific treatment and living in a certain area, regardless where they receive their treatment.

Other than the registries mentioned above, there are “Procedure registries” collecting information about all individuals undergoing a specific medical/surgical/diagnostic procedure and “Exposure registries” containing information about individuals at high risk of a disease due to exposure to hazardous materials in the workplace or environment. The High Altitude Pulmonary Oedema (HAPO) registry of the Indian Armed Forces is an example of an exposure registry.

A key factor that must be kept in mind is that registries are vastly different from routine surveillance systems. While the latter can be broad based taking into account a variety of diseases to be monitored (primarily for incidence), the former are strictly disease specific and cannot be broad based, for e.g., a cancer registry, Cardio Vascular Disease (CVD) registry, etc.

Formalization of a DR for the Armed Forces is a felt need, particularly when we consider the fact that we have a captive, dependant, population serving under a common umbrella of the Armed Forces Medical Services (AFMS). In keeping with modern times and the need for practicing evidence-based medicine, it is imperative that we have an

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existing repository of data related to patient care in terms of epidemiological parameters, clinical profiles, regimens used, and treatment outcomes. This becomes a prerequisite to formulate policies, allocate resources and improve quality of care.

The AFMS has certain inherent strengths that make the creation of a DR both feasible as well as viable. These have been amply brought out while establishing a joint replacement registry in the AFMS.⁴ While the framework exists for formulating a registry, there are certain vital concerns that need to be addressed before embarking on the task.

Type of registry

The AFMS caters to a dependent clientele and hence can uniquely formulate a population-based registry with a link up between service hospitals to create a central registry. Exposure-based registries, such as the HAPO registry and the HIV/AIDS registry of the Armed Forces, are already functional. With a robust follow-up data, these can actually function as full-fledged disease registries. At present, Joint Replacement Centers and Malignant Disease Treatment Centers maintain individual databases. By simple measures of standardization of protocols and linking their databases, there is an immense potential for creating a formal joint registry and cancer registry, respectively.

Data genesis

Effective data compilation is a prerequisite for a registry and lack of same is a stumbling block as on date. The only data that are centrally compiled are the admission and discharge (A&D) data from hospitals, which can at best give the incidence estimates. Most chronic diseases are followed up on OPD basis. Unfortunately, the outcomes are not recorded and no follow-up data are generated.

Data handling

A DR ideally requires a database buildup both at source (hospital) and at a regional/central level with networking for access and retrieval. A good registry also uses standardized methods to maintain data quality in terms of accuracy, validity, completeness, and comparability, and provides rapid or real-time feedback to facilitate the most appropriate care delivery. Currently, there are various Hospital Information Systems (HIS) platforms in the AFMS and there also exists a secure communication network in the form of Army Intranet. Unfortunately, our platforms are not able to communicate with each other across services. This prevents us from building up the requisite data for a registry.

HR capabilities

A fully functional DR requires dedicated and trained personnel involved in data capture and entry to ensure standardization, accuracy, and validity. Clinicians and the supporting para clinical specialty staff can be expected to fill out standardized patient cards/forms on contact. But it would require a dedicated, trained staff to feed these data into the registry in a reliable and accurate manner.

Way forward

The way forward would therefore appear to be to take up the task in a phased manner. The first step should be to decide on one or two key diseases to build a registry. This could be certain cancers, joint replacement, or CVD, since the data related to these are already being compiled at respective centers. The next step would be to either create a software to manage the data entry and database or modify existing HIS platforms to capture the data with the capability for data sharing. Simultaneously, the HR requirements in terms of identifying and training personnel need to be addressed. Once this select registry is stable and performing for at least a period of 3 years, further diseases can be added.

It can be realized thus far that AFMS is custodian to a large amount of medical data. Establishment of a DR is a step in the right direction to utilize this invaluable resource. To keep up with the rapid evolution of evidence-based medicine, ensure optimal utilization of meager resources, prioritize areas for quality healthcare delivery, and lastly to ensure appropriate policy making, it is high time that the AFMS endeavors towards establishment of disease registries.

Conflicts of interest

The author has none to declare.

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