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DIABETES REGISTRIES

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Abstract

As per International Diabetes Federation (IDF) Atlas – 2015 report, Diabetes was one of the worst centurial global health hazards. Its prevalence among people aged 20-79 years at 8.8% in 2015 was estimated to rise to 10.4% in 2040 (Sreedharan, J. (2016).). Another report reveals that about five million people are enduring with Diabetes universally and the number is expected to expand to 51% by 2045, due to rising obesity, growing unhealthy lifestyles, and the aging population. Furthermore, half of the populace living with Diabetes is not even aware that he/she has Diabetes (Saeedi, P., Petersohn, I., Salpea, P., Malanda, B., Karuranga, S., Unwin, N., & IDF Diabetes Atlas Committee. (2019)). With extensive public health ailments, Diabetes Mellitus merits a disease for establishing a registry, and maintaining a data about the health conditions of patients and the treatment received over a period. Registries would be highly beneficial in achieving insight by gathering large-scale data and making knowledgeable decisions. These are extremely useful instruments capable of judging the value of therapies in the clinical practices for Diabetic patients, conducting trials, and conceding areas where better results can be attained.

INTRODUCTION

Diabetes Registries

Diabetes Registries is a novel healthcare concept that originally commenced in the USA Healthcare System. This concept of tracking , cataloguing , and sharing relevant data is now getting on worldwide and is facilitated by crowdsourcing and increased information-sharing. Upgrading healthcare quality and the dissemination of national and international treatment guidelines is the central objective of these registries. Vast benefit in view ,countries with some form of Diabetes Registry had risen from 23 in 2011 to 30 in 2014 (Bak, J. C., Serné, E. H., Kramer, M. H., Nieuwdorp, M., & Verheugt, C. L. (2020)). Largely, registries are highly successful in the appraisal and ameliorating of the quality of Diabetes Care by using specified guidelines as a benchmark e.g., cautioning schools/colleges to remain on guard against obesity in the youth by encouraging children to participate in obligatory physical activity for at least one hour a day and forewarn the adults in reshaping their lifestyle and make use of appropriate physical activities. These are also source of systematically documenting weight, HbA1c, lipid profile, and insulin treatment; besides recording many other variables.

A classic registry accounts for the well-being and lifestyle culture of the patients who would like to participate in the study. It lists Type 1 and Type 2 Diabetes in 18 and older people besides allowing instantaneous access for retrieving information about names, date and location of birth, email addresses, and relevant data from respective medical records. These details are not only clinic-sourced but are extended for online enrollment to any Diabetic who qualifies specific

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criteria. Registries are of particularly useful in preparing peer-reviewed publications for the professionals. Greater comprehension of the patient's perspectives by the physicians will benefits them more in providing better treatment and education of their patients. Registry data also facilitates in sifting study participants for clinical experimentations and related studies.

Scandinavians are far ahead of the rest of the world in this subject. These countries are using Diabetes Registries in collecting and sharing diabetes information at national levels and producing efficient public health policy (Brown, 2019). Their dynamic registries permit an easy examination of the occurrences and the related risk factors. By pressing a button, they're able to observe 10- 20-year Diabetes trends for the entire nation. Registries thus have become the most valuable reservoirs of health information. Large-scale information also helps them in categorizing participants for clinical trials and relevant studies. A registry also provides immediate access to the potential participants with the right age, Hypoglycemic, and Hyperglycemic events history. Generally, these registries can be of two types that deal with hospital-based and or population-based data. This concept is in practice in many countries in different forms as: -

India

India still has no population-based registries; however, they are planning to start with Diabetes Registries in two major cities i.e., New Delhi and Madras by involving local hospitals and clinics. However, India does have many Diabetes Research Centers that produce substantial statistics for population-based research (Diabetes Epidemiology Research International Registry Group. (1987)).

Bangladesh

The Diabetic Association of Bangladesh (BADAS), manages a massive network of its kind that renders far reaching care to the Diabetics by operating 68 related associations in country's 64 districts with a nexus of smaller hospitals. Their motto is 'no Diabetic shall die untreated .E-Registration of diabetic patients in Bangladesh has just started to help delivering quality care for patients living with Diabetes through analyzing epidemiology.

Japan

Japan has three categories of Diabetes registries. The Central Registry manages data on young Diabetics. About 60% of Diabetes cases in Japan are contained in this registry. The second Population-Based Registry examines school children screened by urine testing. The third registry identifies cases from hospitals and clinics (Diabetes Epidemiology Research International Registry Group. (1987)).

Malaysia

The National Diabetes Registry (NDR) of Malaysia keep a track of Diabetics health care standards at their public primary care clinics. They have a well-developed web-based data collection system, operating since 2011. Their Diabetes Registry collects/ shares quality data, draws comparisons between current practices and existing guidelines for care, gives feedback and generates research insights, and carries out evaluation and planning of healthcare service.

Registries- a valuable asset to deal with Diabetes

Diabetes Registries are comparatively simpler to manage because accurate case definition is easier than other diseases i.e., Coronary Heart Disease and Cancer. These registries enable us to find out why diabetes affects certain population groups at a disproportionate level i.e., one group of people is more susceptible to higher hemoglobin A1Cs or lower continuous Glucose Monitoring (CGM) usage. Registries enable us to determine who is and is not getting due medical care and initiate measures to reverse that trend.

Looking at the bigger picture, these registries are a source of greater help in determining how biology, behavior, and the environment e.g., pollution, transportation, sleep, food security, etc. — influence Diabetes trends among the general population and in specific demographic and socioeconomic groups. These data can be a valuable surveillance instrument for managing

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healthcare policy, while determining economic effects of Diabetes, evaluating prevention programs, and therapeutic interventions.

Diabetes Registries also help in studying how the geographical variability works on this disease. For instance, a youngster in Finland is twenty times more likely to develop Diabetes than a child in Japan, a difference that is greater than that for Coronary Heart Disease or Cancer (Diabetes Epidemiology Research International Registry Group. (1987)).

Since Registries are now well established in systemizing collection, storing, restoring, studying, and distribution of data on persons who either have a particular disease or in risk of health effects. These can similarly be useful in the management of infectious diseases. Registries can also play a leading part in examining the prolonged COVID-19 symptoms, after-effects of the disease and assessing the efficiency of the vaccines being used. Registries can be very useful in studying the later phases of this pandemic.

Necessity of Diabetes Registry in Pakistan.

IDF Diabetes Atlas 9th edition has noted that Diabetes currency in Pakistan has risen to 17.1%, which is alarmingly 148% higher than the previous report. In 2019, more than 19 million adults in Pakistan were Diabetics – leading them to risk of life-threatening complications. According to a WHO study the current prevalence of type 2 Diabetes Mellitus in Pakistan stands at 11.77% which is 11.20% in males and 9.19% in females. Its occurrences in Sindh stand at 16.2% in males and 11.70 % in females and Punjab it is 12.14% in males and 9.83% in females. According to another report by the International Diabetes Federation (IDF) Diabetes Atlas 10th Edition, Pakistan is positioned third in Diabetes prevalence following China and India at 33 million living with Diabetes. IDF also reveals that 1 in every 4 live births is affected by Hyperglycemia in pregnancy.

Around 10 Million Children in 8-10 years of age are now confronting childhood Obesity in Pakistan and if immediate steps are not taken, these children would also become Diabetics in the next few years (Staff Reporter. (n.d.)). Despite such a grave situation, merely 9 % receive any treatment and a much smaller proportion of these patients receive constant regular treatment (Basit, A., Fawwad, A., & Baqa, K. (2020).). Our urban slums where nearly half of the poor live are in the worst situation. There is a need to identify such patients for treatment who are currently being lost. Healthcare Policies are prepared/implemented based on reliable information, but regrettably, Pakistan has paucity of data concerning various health statuses among its populace, that's why we are unable to frame valuable diabetes policies.

The Pakistan Diabetes Registry (PDR) is the answer to this grave situation. It would primarily focus on the Type 2 Diabetes Mellitus (T2DM) state, its consciousness, and the availability of treatment in primary care services. The PDR would be a great help in studying the access, continuity, and affordability of a treatment that greatly remains undetected and unregistered in the country.

A modest effort has already been made to fulfill the need of forming Diabetes Registries. An MOU has been signed between Health Research Advisory Board (HealthRAB) and a local pharmaceutical firm to create the Diabetes Registry of Pakistan (DROP) for people with Type 2 Diabetes, people with Diabetic Foot Ulcers, Peripheral Vascular Disease, and women with Gestational Diabetes, reports Dawn published on October 9, 2021. However, this mission is to be undertaken at the national level systematically. Steps to be followed for designing a registry would include:-

a. The purpose of the registry.
b. Identification of the key stakeholders.
c. Building a registry team.
d. Defining the data set, the target population, and the periodic evaluations.

Ideally, a registry should have a pool of 4000- 5,000 volunteers / enrolled patients comprising roughly 1/3 of type 1 and 2/3 of type 2 individuals. An appropriate number of those are required to be spread out in the country as considered

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suitable.

Simultaneously, the appropriate number of health workers needs to be gathered, and a curriculum to up skill them be created for teaching them about deciphering research data and developing a better understanding of digital data and wearable diabetes technology. With such an educated health workforce, we can gather health data more efficiently to influence a significant change in health care.

Data in these registries is collected through many means the world over i.e., manual entry, automated data derived from the electronic health records, or by linkage with other national databases and reliable registries. Mostly, registries combine all of these methods to gather their data. Data will primarily be obtained from hospital sources providing clinical, laboratory, and education details. Information to be collected for diabetes registries for the populations under study will be standardized as under:-

a. Patient's name, date of birth, sex, race, and place of residence at the time of diagnosis.

b. Date of diagnosis and the date of first Insulin Administration.

c. Additional information of relevance to be obtained from medical records or individuals.

Challenges for Diabetes Registry

Some of the worst burdens are felt in urban slums where nearly half of the poor Pakistan Population lives. There is a need to identify and retain these patients for treatment who are currently being lost. For producing a valuable registry, it is essential to seek the cooperation of all the hospitals i.e., allowing researchers to examine hospital and physicians' records within the defined geographical area. Many hospitals may not be forthcoming for fear of "stealing" patients, checking medical care inviting criticism on diagnostic or treatment practices, cost, and inconvenience. However, such resistance can best be dealt with by:-

a. Discussing the project with the relevant medical staff and assuring them that the research will purely be used for scientific purposes. Research workers at the hospital can be advised to be careful in causing lesser inconvenience to the hospital and focus on the registered cases only.

b. If this course of action fails, a letter addressed to the hospitals from either WHO or researchers from developed countries can be beneficial. It will be hard for healthcare administrations to disregard an objective request for participation in an international initiative. Alternately, ingress to the medical records can be looked for through governments stepping in i.e., a request made by the Ministry of Health will be more effective.

NIH Pakistan Role

NIH can play a pivotal role in this project. We may create a cell in TECH Department to pioneer this initiative and prepare a case for the Health Ministry. Diabetes Registry models being followed by other countries can be studied in detail to work out the best possible plan.

Conclusion

Registries can greatly facilitate evidence-based care for all patients. These are powerful tools to monitor clinical data of the population, track trends, and determine why Diabetes affects certain population groups at a disproportionate rate. They determine the necessary steps to start reversing that trend and improve team-based care. Despite usefulness, registries are still constrained by unidentified findings among a community/ denominators, who are not the actual representatives of cases discovered in the population sample. Moreover, these are disease-specific and require hardware, software, and sophisticated maintenance tail. Registries also need specifically trained people who are competent enough to exercise data entry and data maintenance.

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