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Mini review

Promoting Construction and Utilization of Integrated/Comprehensive Healthcare Database Aiming for DX of Disability Policy Toward a Symbiotic Society

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Abstract

In recent years, the majority of the population has come to live longer with various health issues. In this research, we will explore the ideal way of efficient, effective and appropriate realization measures against changes in the disease structure in Japan through the construction and utilization of a comprehensive health care database. WHO's ICF (International Classification of Functioning, Disability and Health) can be applied to the health status of all people, and "disability" can be reassessed as "support needs of consumers." In addition, the Ministry of Health, Labor and Welfare has begun to build and utilize a database (NDB) that adds "Long-term care insurance data" and "Disability welfare related service data" to "Medical receipt information / Information such as specific medical examinations." These "health / medical/long-term care / disability" databases should be used as a comprehensive healthcare database, and should be constructed and utilized in future community-based comprehensive care systems, aiming for "Contributing to improving the QOL of all residents by promoting database analysis and data utilization centered on local government."

Keywords: Integrated/comprehensive healthcare database, EHR (Electronic Health Record), PHR (Personal Health Record), individual life course, outcome.

Introduction

What kind of information is needed for the long-term health care in the future

The GBD 2010 (2010 Global Burden of Disease study) since 2007 revealed for the first time that the world's disease structure has changed dramatically in recent years [1, 2]. In other words, "Most of the world's population has been able to stop premature death due to advances in medical care and development. On the other hand (ironically), people have come to live longer while having health issues such as burdens such as from mental and behavioural disorders, musculoskeletal disorders (chronic pain and injuries), and risk factors such as obesity and lack of exercise [3-8]."

Then, what kind of information should be collected in order to realize efficient and effective measures based on EBM (evidence-based medicine) in such an era? The information re-

quired as an outcome indicator for intervention assessment of health care and welfare services is not only limited to indicators such as "mortality rate." After a life has been saved, I think that various factors surrounding "Health Condition," such as body functions & structure, environmental factors, activities, participation, and personal factors, are indispensable as information when living a daily life or working life while having various sequelae and disabilities. Already in 2001, the ICF (International Classification of Functioning, Disability and Health) [9] was published by WHO (World Health Organization). With this as an international standard, the concept of disability is not limited to so-called "persons with disabilities," but applies to all people.

From this perspective, we have focused on the prognosis/outcome of trauma after the end of acute care, and have explored ways to realize an efficient and effective information system [10, 11]. Many of the injuries can be a cause of sequelae and dis-

abilities. Therefore, in recent years when the mortality rate has improved sharply due to the improvement of medical standards, it is needed to concretely grasp the “living function” and “Social environment factors” of people who live with sequelae and disabilities after acute phase treatment. In this way, it will be possible to re-evaluate “persons with disabilities” as “people with support needs [12].” In this research, we will explore the ideal way of efficient, effective and appropriate realization measures against changes in the disease structure in Japan through the construction and utilization of a comprehensive health care database.

Proposal of a Comprehensive Health Care Database in Society 5.0

On the other hand, in Japan, the efforts of e-Japan were started in 2001 [13]. In other words, it is an initiative for “all people can actively utilize IT (information technology) and enjoy the benefits to the maximum.” In recent years, as a Society 5.0 society [14] (IT society), a human-centered society that aims to achieve both economic development and solution of social issues by highly integrating cyberspace and physical space. In the Society5.0 society, we should make the best use of ICT (Information and Communication Technology) [15] to realize “With Coronavirus Society” which can be said to be a society that includes health risks and vulnerabilities.

Looking at the current state of health information services in Japan, long-term care big data has been added to health care information such as NDB (National Database) [16, 17], and anonymization that can be collated based on the consent of the person. Electronic management is progressing as data, which can be used by third parties such as local governments and researchers. On the other hand, in the medical field, there are many cases where information is still stored in individual medical institutions. However, electronic medical record has become widespread as an “EMR (Electronic Medical Record).” EHR (Electronic Health Record) [18, 19], which records all personal medical care and health/long-term care information in electronic media, is limited to a part, and its dissemination is an issue [20].

Furthermore, in recent years, it is planned to build a “disability welfare-related service database (tentative name),” which is an extension of the “Comprehensive Support System for Persons with Disabilities [21]” that connects municipalities/business establishments and the National Health Insurance Federation to this EHR for health, medical care, and long-term care. Japan’s disability welfare policy has been proceeding basically in line with the ICF philosophy since the revision of the law following the ratification and entry into force of the Convention on the Rights of Persons with Disabilities in 2014. However, it is presumed that most of the existing data collected and accumulated by this system is conventional data based on the medical model. Therefore, it is necessary to add information such as QOL as data from the viewpoint of the patient/party/family, etc. at the stage of making it one of the relational databases in the health information service. For that purpose, the utilization of cloud and mobile devices, which have been diversified and spreading in recent years, will be useful. With that in mind, we are currently embarking on “Study on the usefulness of data utilization using mobile devices in the field of disability health.”

Toward DX of Comprehensive HealthCare Policy for a symbiotic society

Once a comprehensive database system for health, medical care, long-term care, and disabilities as described above is constructed, it can be used as a PHR (Personal Health Record) [22-24] to realize an individual “comprehensive healthcare database.” Of course, data standardization will be indispensable for matching data such as health and medical care based mainly on ICD (International Statistical Classification of Diseases and Related Health Problems) with disability databases mainly based on ICF. However, in Japan, which is regarded as the world’s top runner in terms of aging, it will be necessary to promote its construction and utilization, in order to broadly understand the meaning of “disability” and make the disability database “a comprehensive health care database throughout the life of an individual.”

This is because, if we look at a comprehensive healthcare database from the perspective of PHR, the information system infrastructure and configuration data can become a “common information infrastructure, common language” that stabs the conventional fields by vertical division. This makes it possible to add a natural science perspective to the long-term prognosis/outcome of chronic injury and illness in the field of disability welfare centered on the humanities. Like illness and injury, disability is also regarded as “one of the health hazards,” and how about trying to change the conceptual image of “disability” and “health” from the post World War II period? In other words, we will promote the construction and utilization of the “disability database” based on the expanded concept as a “general health care database.” By doing so, it will be possible to establish the health promotion of people living with disabilities as the “disability health field (tentative name)” and to take health care and welfare measures for all people. The following various prospects are expected to promote the construction and utilization of a comprehensive health care database. Digital transformation (DX) that “aims to realize a symbiotic society [25]” by providing a comprehensive healthcare database system to local governments of community-based comprehensive care systems as “an information infrastructure that can aim for a society without disparities and breaks” (DX) also seemed to be promising.

The Comprehensive Healthcare Database has the following Promising Prospects

- It is expected that the quality of EHR/PHR will be improved and refunded by enhancing outcome information.
- “Information infrastructure for health measures” will be completed. This clarifies the division of roles between the national and local governments. In other words, the national government will promote the construction, management, and utilization of EHR/PHR (data standardization, analysis model presentation, human resource development, enlightenment, etc.). Municipalities can use data to drive evidence generation. This makes it possible to promote the division of roles toward the transition of the comprehensive community care system.
- We can re-evaluate measures for persons with disabilities. Re-evaluating persons with disabilities as consumers with

support needs can be expected to contribute to the qualitative improvement of independence support measures.

- We can create a field of disability health to get an information infrastructure which will be created to implement independence support measures for persons with disabilities based on same grounds. As a result, it seems possible to unify the policy implementation system into the same measures regardless of the presence or absence of disabilities. Therefore, it is possible to shift the paradigm through DX in policies related to health measures for persons with disabilities.
- By promoting the utilization of “health, medical care, long-term care, and disability” PHR (which includes EHR information), a “common language” can be created to promote the “health of all people” policy. From this point of view, DX is possible as an information base that contributes to health measures in a “coexistence society of all people” regardless of the presence or absence of disabilities.
- If a mechanism for accumulating existing medical and welfare data is constructed as the EHR part of the Disability Registry, researchers such as medical professionals will not have to devote their efforts to the part of “collecting data.” This will enable the comprehensive community care system to focus on the PDCA cycle for evaluating health, welfare, medical and long-term care measures without disparities or breaks in each region.
- It will be easier to include perspectives from various fields such as service providers parties/persons concerned.
- Epidemiological information on long-term prognosis/outcomes such as trauma, for which there was not much information so far, can be obtained. This makes it possible to observe and record long-term pathological information after long-term survival for surgical diseases that are relatively invasive. By doing so, it can be expected to monitor pathological conditions such as reactions/side effects and complications to the treatment of specific diseases in the acute phase, gene damage, and effects on the immune system, such as medical diseases. Japan, which has experienced traffic wars and a super-aging society ahead of the rest of the world, has a responsibility to proactively disseminate medical and welfare evidence of people with risks and vulnerabilities.

Summary and Policy Implication

For people with disabilities, ICT is useful not only as a support device, but also as a driving force in labor for individuals with a sense of purpose to shift to independent living in the community. Therefore, since the ratification and entry into force of the Convention on the Rights of Persons with Disabilities (2014), efforts to re-evaluate persons with disabilities as “living people with support needs” and to prepare a social support environment have been expanding. A comprehensive healthcare database can be expected to be constructed by adding Disability Database to EHR/PHR, which is medical big data, to enhance outcome information, and connecting mobile devices to incorporate the perspectives of patients, parties, and families.

The main requirements for providing high-quality health, medical, welfare, and long-term care services for the QOL improvement measures of all individuals according to the actual conditions of each region toward the comprehensive community support system that will shift to 2025 will be: The national government needs “(1) collection / accumulation of failure data / enhancement of comprehensive DB, (2) development of analysis model / human resource development utilizing comprehensive DB,” and, what is needed for local governments is “realization of efficient and effective measures to be carried out in collaboration with industry, government, academia and residents based on regional diagnosis utilizing big data such as comprehensive DB.” In this way, we will be able to push forward with the promotion of DX through a comprehensive database toward a vibrant and advanced health country that Japan is aiming for in “Healthcare 2035.”

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None

Conflict of Interest

For this study, none of the authors have a COI status to disclose.

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