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Minireview

How Should We Enhance the Comprehensive Health and Medical Planning Platform in Japan?-Proposal towards “Promotion of Evidence-Based Health and Medicine for People with Sequelae, Disabilities, and Other Chronic Conditions”

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Abstract

In recent years, the burden of disease worldwide has shifted to non-communicable diseases, and there is a need for an enhanced clinical efficacy database that contributes to the management of chronic stage injuries and diseases including sequelae and disabilities. In Japan, on the other hand, in the Regional Comprehensive Support System, which is set to start in 2025, the national government is required to develop a base for information platform so that the regional governments can provide comprehensive measures without breaks and gaps. This study presents strategies focused on the treatment of chronic health problems. Throughout this study, the change from “Heal” to “Care” is mentioned, and the need for researches on this topic in Japan is described. First, I described the establishment and utilization of a medical and health welfare database for people with sequelae, disabilities and other chronic diseases etc. (hereinafter “chronic conditions”) while surveying the positioning of the national information science center. Next, from the viewpoint of constructing and utilizing a database based on existing data, I proposed a research plan to realize it. Eco-epidemiology is one of the ways to realize it, but in promoting it, exploratory analysis should be promoted in consideration of Ecological Fallacy to aim at Hypothesis Generation. These are important because they could serve as a basis for high-quality health policy for all citizens in a mature society.

Keywords: evidence-based medicine, multiple chronic conditions, sequelae, disability, database

Introduction

The authors have proposed “promotion of evidence-based health and medical policies for independent persons with disabilities” as a solution to the challenges of disability reform in Japan [1-3]. In this article, I first review trends in the information science center at the NIPH. In addition, I propose “construction and utilization of medical and welfare databases for people with chronic conditions,” as a measure to enhance the comprehensive healthcare integration platform necessary for the region to plan “comprehensive care without breaks and gaps [4].”

The Role of the Center for Public Health Informatics

In recent years, in Japan, public expectations for “Evidence-based medicine (EBM)” and “Evidence-based public health / health policy (EBHC / EBHP)” have increased. The National Institute of Public Health (hereinafter “NIPH,”) established in April 2002, is an organization of the Ministry of Health, Labor and Welfare that conducts education and training for health, medical and welfare staff, and conducts related research [5, 6]. According to the Ministry of Health, Labor and

Welfare’s organizational order [7], the NIPH is stipulated to be an organization that “doing the research and study of the training and training of staff and other persons related to health care or health and sanitation, and the application of science and technology related to health care and health to them.” According to the Ministry of Health, Labor and Welfare’s organizational rules [8], the affairs of the Center for Public Health Informatics in NIPH are stipulated, “The Research Information Assistance Research Center collects information on, Evaluation, use and provision (Article 551 of the Regulations).” The NIPH has four specialized fields and libraries registered as designated collaborating research centers by WHO, and conducts investigative research on public health, etc. in collaboration with WHO Headquarters and WHO Western Pacific.

The NIPH plays a central role in the development of domestic and foreign public health at home and abroad, in accordance with its five-year vision for its organization and operations. Organizational activities, including the Center for Public Health Informatics, are published as an annual report in the journal “Ho-

ken Iryo Kagaku [9,10].” According to the activity report for FY 2018, the Center for Public Health Informatics has conducted all processes related to healthcare. Related research was conducted. Themes cover a wide range, including theoretical research, data analysis, information system construction, and epidemiological research. In FY2018, various studies were conducted mainly from the viewpoints of (1) establishing an information base on health care, (2) evaluating and applying scientific information, and (3) establishing a methodology for that. [Table 1] shows the main activity reports for FY2018.

Proposal for Evidence-Based Reform of Medical, Health and Welfare Policy for People with Chronic Conditions

Construction and utilization of “medical, health and welfare database for people with chronic conditions”

In recent years, many countries have faced a changing disease structure, and the global disease burden has shifted to non-communicable diseases [11]. The World Burden of Diseases, Injuries, and Risk Factors Study (GBD) 2010 analysis of Disability-adjusted life years (DALYs) over the past 20 years (1990-2010) shows that the burden of illness is now shifting, mostly to musculoskeletal, psychiatric, and injuries, which are increasing as people live longer [12]” (Table 1).

Table 1. Main activities of the Center for Public Health Informatics in recent years. (Partially excerpted from FY2018 activity report [9]).

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| <ol style="list-style-type: none"> 1. Research on establishment of information base on health care Development of information collection system using ICT, database construction related to various health and medical information etc. 2. Research on evaluation and application of scientific information 3. Methodological study on health information 4. Human resource development for health and medical information 5. “Specific health checkup / specific health guidance database project” 6. International Cooperation: WHO International Statistical Classification (WHO-FIC) Cooperation Center Function |
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On the other hand, Japan’s population are aging ahead of the rest of the world and medical and social security systems are require a shift from “Cure” to “Care and support [13].” In order to invest limited resources more efficiently, health information (evidence) that contributes to the evaluation of intervention effects and measures or policies will be more important in the future. The construction of a database for collecting and analyzing patient registration information on patient medical information (diagnosis and treatment contents etc.) at medical institutions nationwide is being promoted for each disease and illness. At present, the lack of understanding of the outcome information (e.g., nursing care / disability) necessary for the evaluation of the effects of follow-up surveys is an issue because most of the information is established by the clinical medical society. “Clinical

effect database” is needed [14].

Towards Realizing a Clinical Efficacy Database in Japan Proposal of research plan on construction and utilization of medical and health welfare (nursing care) database for persons with disabilities

Purpose and overview

Follow-up of outcomes is important in assessing clinical efficacy. However, most of the current clinical databases are constructed by separate medical academic societies, and the problem is that follow-up research on nursing care and disability is inadequate. To solve the issues, it is necessary to build a database that links medical care with nursing care and welfare. Both of these data are captured by local governments such as prefectures and municipalities. Therefore, the authors propose a research plan on the construction and utilization of a medical and health welfare (nursing care) database for persons with disabilities in order to solve the above problems. In other words, this is a plan to build a database centered on local governments, together with the creation of a mechanism for collecting, storing, and utilizing information and technical support.

Academic uniqueness / creativity

As one of the feasible outcome information, we proposed construction of a health and welfare information database of disability and promotion of utilization in various regions. At present, for example, the certificate of the physically handicapped (health, medical and welfare information of the handicapped) is legally obliged by the head of the local government to manage the ledger, but the effects of the health promotion measures for the handicapped and the evaluation of the measures it cannot be said that the situation is being used. In the future, this study will focus on local governments as “creating an information environment” in order to promote more efficient and effective disability health and welfare measures and promote community development to support the independent health promotion of persons with disabilities. The aim is to build a database of medical and health welfare (nursing) for persons with disabilities and to propose a regional model for collecting, accumulating and utilizing information (Figure 1) [1-3].

The information stored in the database to be constructed is not new survey data, but information already held by a local government such as a municipality. Therefore, it is not limited to simply constructing a database, but local governments can take the initiative and operate relatively cheaply and sustainably. In addition, the uniqueness and creativity of this research plan lies in the combination of “model development” for collecting, accumulating, and utilizing practical and practical database information that is academically significant.

How to promote care research

In this study, I focus on medical and health welfare (nursing) information for people with disabilities as one of the feasible outcome information. In the present situation, for example, the ledger of the local government is legally obligated to manage the ledger’s notebook certification information (health and medical welfare information of the disabled). However, it cannot be said

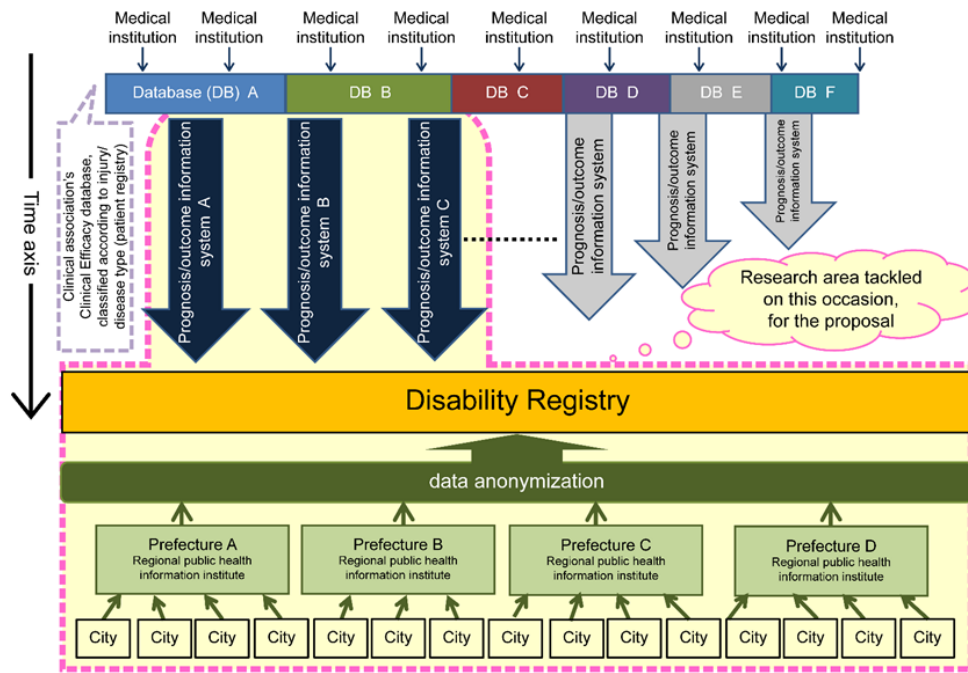


Figure 1. An image of the medical welfare database for people with chronic conditions [3].

that they are utilized for the effect of health promotion measures for persons with disabilities and evaluation of the measures. Therefore, in the future, it is necessary to further promote efficient and effective health and welfare measures for persons with disabilities, and to promote regional development that supports the independent health promotion of persons with disabilities. As a necessary information infrastructure development for this purpose, in this research, we build a health and medical welfare (healthcare) database for disabilities centered on local governments, and clarify a regional model for collecting, accumulating and utilizing information.

Since this system manages data in common throughout the country, the data will be collected in each prefecture in a unified manner by adopting a system that complies with the standard of operation guidelines for the clinical effect database. Data transfer from the local government system to this system will be performed in the prefecture.

Since this system manages data in common throughout the country, the data will be collected in each prefecture in a unified manner by adopting a system that complies with the standard of operation guidelines for the clinical effect database. By sending anonymized data from these data to the data collection server in the National Institute of Public Health, it becomes possible to collect and manage data nationwide.

This project does not require the consent of the person as it is carried out as a part of the work of the local government, but if it is necessary for collecting data in the future, we will obtain the individual consent. The research ethics review will be conducted by the Research Ethics Committee of the National Institute of Public Health. For project continuity, the Personal Information Protection Committee and the Data Collection Item Review Committee will be organized in a meeting between the National Institute of Health Sciences and the Regional Institutes of Health to ensure effective data collection management.

Regarding data items, clinical information should be in accordance with the guidelines, and international standards such

as International Living Function Classification (ICF) and WHO-DAS 2.0 should be used. The ICF systematically classifies various different areas related to a person in a certain health condition (eg, what a person with a certain illness or disability actually does and can do). WHODAS 2.0 has been developed by WHO from the comprehensive components of ICF and is used for national statistics in Taiwan and other countries as a comprehensive assessment tool for measuring health and disability.

By the above method, a regional model for collecting, accumulating, and utilizing outcome information will be constructed for the [medical institution center version] and [local government center version].

How to measure care needs

In a ‘care-focused mature society’ that addresses the chronicity of illness requires ‘supportive care and regular monitoring to reduce the severity of disease and maximize individual function and responsibility for self-care’ become. For this reason, the scientific evidence necessary for promoting the EBHP is not the traditional “epidemiology targeting disease-specific factors” but “physical and social exposure.” “Ecological epidemiology [15]” based on the life course approach, including the long-term effects on risks and the interaction between disease factors, becomes even more important.

Ecological epidemiology is a method of examining the relationship between factors and diseases in different regions or countries, by analyzing the region or group unit (country, prefecture and municipality) instead of individuals. In addition, since ecological epidemiological studies usually obtain information from existing statistics, they are far less expensive and time-consuming than other analytical epidemiology such as case-control studies. However, ecological epidemiology may fall into Ecological Fallacy when comparing groups whose background factors are too different, so caution is required [16].

Therefore, the Ecological Study cannot be used for hypothesis testing. For the realization of this study, when using eco-

logical epidemiology, it seems that exploratory analysis aiming at the creation of hypothesis (Hypothesis Generation) should be promoted while considering ecological error (Ecological Fallacy). At the present time, at least the following three themes could be considered as hypotheses to be able to be done for long-term epidemiological analysis of chronic injury and illness that should be mentioned. 1) I wonder if the group living with various disabilities may have more complications than the group that does not have, 2) I wonder if there may be a shorter life expectancy age group in the group living with the disability than in the non-group, 3) I wonder if there might be a relationship between the degree of surgical intervention in treating injury and disease, and the morbidity and prevalence of immune system diseases such as collagen disease.

Related domestic and overseas situations

In the United States, the “Treatment Policy for Trauma Injury” is being promoted in accordance with the “Healthy People,” a guideline for the next 10 years. The health policies for trauma and abuse, for example, in the “Healthy People 2010,” the “Injury and Violence Prevention” (independent health area) and the 28 “Focus Area (focused health area)” it is treated as one of them, and the target (values) of the health policy related to trauma is set. Policy evaluations and reviews are based on epidemiological data, such as trauma surveillance, which will be reflected in health policy guidelines for the next decade. Through this process, the United States health policy on trauma is driven by the EBPH, as is the prevention of diseases such as lifestyle-related diseases.

Regarding trauma surveillance, the WHO / CDC guidelines “Injury Surveillance Guidelines” [WHO / NMH / VIP / 01.02 2001] were published in 2001 by the WHO and the US CDC. The US CDC has also created and published a “Injury Surveillance Training Manual” for instructors and participants, which is used for data standardization and human resource development.

In recent years, the care of patients with chronic diseases has been a health care and public health challenge [17]. Self-management education programs, including arthritis program by the Chronic Disease Self-Management Program (CDSMP), developed at Stanford University in the United States, has spread to many other groups and countries [18]. CDSMP is provided in many countries around the world, and many evaluation studies such as randomized controlled trials have been conducted for various actions related to medical care [19]. In the United Kingdom, working hours regulations introduced in EU member states in the 1990s also called for medical professionals to significantly reduce working hours. At the same time, various measures related to the medical profession were implemented to improve the quality and quantity of medical services that were exhausted under severe financial conditions and ensure sustainability. Healthcare in Britain is mainly provided by the NHS, that is free at the point of use and paid for from general taxation. Since health is a devolved matter, there are differences with the provisions for healthcare elsewhere in the UK [20]. In the United Kingdom (UK), the National Health Service of England (NHS) has adopted self management programs as a key expert partner program and has begun to offer it at all primary health care facilities in the country [21]. The NHS is currently mentioning “self-manage-

ment (SSM)” which is part of the NHS Long term Long-term Plan’s commitment to make personalised care business as usual across the health and care system. SSM is one of six key components of the comprehensive model of Personalised Care [22].

Self-management should be carried out from the perspective of “patients and parties with chronic injury and disease.” Therefore, the role of “supporters such as health, medical and welfare specialists” is merely “support.” It will be the role of the supporter to “create, with social-capitals, environments in which patients and parties can perform high-quality self-management according to their actual situation and values.”□Based on the above concept, we have already started “Study on development and evaluation of self-management program to support social life of post-stroke epilepsy patients” and have been working on the development and evaluation of “Self-management support program for post-stroke problems [23].” It was speculated that the above-mentioned SSM in the UK may be similar to the idea of these authors.

Significance

Trauma is one of the causative injuries that can cause sequelae and acquired disorders even after the medical treatment is completed. Therefore, not only from the viewpoint of primary prevention of injury prevention, but also from the viewpoint of tertiary prevention of functional, mental and social QOL deterioration, a preventive medical approach including long-term prognosis of sequelae, complications, disabilities, etc. In the care-centered society, “accumulation of evidence of injury related to prevention” is important, but Japan is overwhelmingly lacking [2, 24].

In Japan, with the aging of society and the frail elderly population expected to increase in recent years, in the field of nursing care and welfare, “Integrated Care” aimed at integrating medical care with nursing care and welfare has become the tide of care (International Center for Longevity (ILC-Japan) 2012). In order to integrate medical care and nursing care and welfare, it is necessary to switch from a “disease model” to a “care model.” In addition, the international standard of the concept of disability has already been set as the International Classification of Functioning, Disability and Health (ICF) (WHO 2001), and each and every citizen holds dignity. In order to realize a society where independent living can be carried out according to the abilities possessed, it is necessary to evaluate interventions for improving the quality of services based on quality of life and social participation in disability health and welfare policies. Contributing scientific evidence is needed.

In order to solve these issues, members of this research group have been conducting research on collecting, accumulating, and utilizing evidence for the prognosis of trauma such as traumatic brain injury (TBI). We further developed research such as “Study on standardization of clinical effect database” and examined measures to implement measures. Then, for example, it was determined that the patient registration information relating to the acute phase medical treatment for brain injury can be realized by utilizing the Japan Neurotrauma Data Bank (JNTDB) of the Japan Neurotrauma Data Bank of the Japanese Society of Neurological Injury. Therefore, the database construction of “prognostic (outcome) information on the regional cooperation

path after brain injury” is constructed as a regional model in each of Y prefecture and C prefecture / C city (designated city). The construction of a database of “medical / health / welfare (nursing care) information for persons with disabilities” collects the health / medical welfare information of persons with disabilities possessed by municipalities in the model area through anonymization at the Regional Health Research Institute. This will enable the construction and utilization of the “traumatic database of clinical effects of trauma,” which is overwhelmingly lacking in Japan. They seemed to be a high-quality health policy base for all people in a mature society as a “model of clinical efficacy database” that contributes to various chronic injuries and illnesses.

Social Impact of the Task

The realization of the proposal of research plan can be expected to contribute to the following important policies in Japan:

- Improving the local environment to further support independence under the UN Convention on the Rights of Persons with Disabilities [25].
- Contributing to the promotion of important policies for people with disabilities as well as measures against poverty of children and barrier-free universal design in the promotion of the “symbiotic society” which is one of the important policies of the Cabinet Office [26].
- “Goal 3: Health and welfare for all people” in SDGs (17 international goals for 2030, with the goal of achieving a sustainable, diverse and inclusive society) Contribution to the promotion [27].
- Contributing to the social security reform and working reform for medical professionals with a view to 2040 [28].

Conflicts of Interest

The author has no financial conflicts of interest to disclose concerning the study.

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