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Minireview

How to Support Self-Management for Chronic Injuries/Diseases Based On EBM: Evidence-Based Medicine

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Abstract

This study, I proposed how to develop and support EBM-based measures for chronic injuries/diseases in Japan, where access to medical care is guaranteed. This paper introduced future chronic injury/disease strategies of perceptions of disabilities, etc. had been changing. The concept of “disability” has been expanding and should also be regarded as one of the chronic injuries/diseases. It will be necessary to reconsider the long-term prognosis of a specific disability not only as the degree of functional disability, but also as the need for comprehensive care and support required at each stage of life. By accumulating post-injury/disease follow-up data and utilizing the epidemiological cohort information, The author wondered if it would be possible to shift the way of understanding disabilities to the viewpoint of an individual’s life course. Utilization of medical information requires input and outcomes. The author have described the significance of the proposing Disability Registry and proposed contributing to the formation of a healthy and long-life society by enhancing the system by integration of various clinical data.

Keywords: self-management support, chronic disease, injury and trauma, Disability Registry, the Next Generation Medical Infrastructure, life course data

Introduction

In recent years, in the prevention of chronic diseases, not only prevention but also the care of patients with chronic diseases are global health care and public health issues [1]. Irrespective of the cause such as intrinsic or extrinsic, there are many diseases that leave aftereffects and disorders even after lives saving and treatment is completed. The Ministry of Health, Labor and Welfare’s National Lifestyle Survey showed that chronic diseases have an impact on QOL: quality of life [2]. The leading cause of need for “nursing care” for all the care recipients was dementia, but cerebrovascular disease (stroke) was the most common among the severely ill patients requiring care. QOL decline due to chronic illness. Furthermore, looking at the breakdown of those who became “support required,” the No.1 was joint disease, and the No.3 was fracture/fall. Sequelae and disabilities remain after lifesaving and treatment, these injuries and diseases cannot be overlooked as health problems with reduced QOL. It can be said that the importance and necessity of social lives support for people living with such various health problems (hereinafter referred to as “chronic injury/disease patients”) are increasing even in Japan.

In the future, as a world where Japan is heading, the movement toward the achievement of Society 5.0 [3] (IT society) and SDGs: Sustainable Development Goals [4] is beginning to move in conjunction with various fields. In order to achieve a diversified symbiotic society [5,6], it is necessary for a person with a

chronic injury or disability, to live a life similar to other people and obtain information, that is, assurance of information accessibility [7] is required. This paper will propose how to develop and support EBM-based measures for chronic injuries/diseases in Japan, which is also called the “world’s model of the UHC: Universal Health Coverage [8],” and where access to medical care is guaranteed.

Future chronic injury/disease strategy

Perceptions of disability and images of people with disabilities have changed

Looking at the causes of disability for people with physical disabilities (18 years old and over) at home in the 2013 edition of the White Paper for the Disabled (Cabinet Office) [9], the proportion of diseases and accidents is high, but unknown are also high. Among diseases, the proportion of non-infectious diseases is high, and disorders are also caused by lifestyle-related diseases and diseases of unknown cause. It can be seen that chronic injuries/diseases are the cause of considerable disability.

“The subject is the patients/other parties.”

Let’s take a look at the historical background of measures for persons with disabilities in Japan. Before the World War II, people with disabilities had been designated as “objects of poverty” in the “Relief Act” (1929) as a general measure against poverty.

Or it was said that the mentally handicapped had been only subject to security and enforcement [10]. After World War II, welfare was placed in the Constitution of Japan and a movement to promote employment for general employment emerged. However, the idea of normalization did not spread until the movement of the International Year of Persons with Disabilities (1981) with the theme of “full participation and equality” occurred in the 1980s. For this reason, Japan’s measures for persons with disabilities centered on institutional facilities. After that, certain measures for community-based welfare were advanced, and various infrastructure development was promoted. However, it is said that the implementation of the UN Convention on the Rights of Persons with Disabilities (2006) and ratification in Japan (2014), “guaranteeing the human rights of persons with disabilities,” was insufficiently implemented domestically [10]. By “Disability Rights Convention,” the human right to leave the protected environment and become “independent” while accepting illness and disability is secured. In order to achieve “revival of rights” and “reconstruction of life,” which are the principles of rehabilitation, it is necessary to further disseminate the concept that “the subject is the patients /other parties.”

From ICDH to ICF -From diagnoses to symptoms-

Looking at international trends, the WHO published ICDH (International Disability Classification) in 1980 [11]. As a result, an analytical viewpoint was added to the way of understanding disability itself. In 2001, ICF (International Classification of Living Functions) was published [12]. This has led to the classification of various health issues for all people, not just those with disabilities. Furthermore, in ICF, life function was used as a classification criterion instead of a specific disease name. As a result, the concept of “from a medical model to a social model” was introduced [13]. It will be necessary to reconsider the long-term prognosis of a specific disability not only as the degree of functional disability, but also as the need for comprehensive care and support required at each stage of life.

The concept of “disability” has been expanding

Since the ratification and entry into force of the 2014 Convention on the Rights of Persons with Disabilities, Japan has been reassessing its measures toward its realization under various related laws and regulations. The people who were called “persons with disabilities” in Japan in the past are “independent people,” but they still are considered as in socially weak positions. The concept of “disability” is expanding, and in 2013, pathological conditions caused by intrinsic diseases such as intractable diseases were added to the comprehensive support law for persons with disabilities [14]. From these perspectives, it can now be said that “disability” should also be regarded as similar to/one of the chronic injuries/diseases.

What would be the foundation of social life support for chronic injuries/diseases?

Access to medical care is guaranteed [15], and the shift to a regional comprehensive care system (= regional comprehensive medical care) is progressing [16] In Japan, a new health strategy that performs social support for self-help and mutual assistance for self-management by patients and families is needed. The au-

thor is currently working on the issue “How should we realize self-management support system for people with disabilities and chronic health problems based on scientific evidence?” Out of the following three recommendations [17,18] for that purpose, this paper introduces the “disability registry,” that is, the construction of an information database. Table 1 gives an overview of the three recommendations made [11,19-25].

Why is it necessary to build a disability registry database (“Disability Registry”)?

In the comprehensive community care system that is being developed by 2025[26], the region is required to operate without disparity or discontinuity depending on the field or disease. To this end, it is necessary to establish a “system for the local community to support self-management of health problems by the residents such as patients and families based on scientific grounds.” On the other hand, it is said that there is an overwhelming lack of follow-up data on trauma among medical data related to health in Japan [27]. Therefore, the author considered that post-injury follow-up data should be accumulated and the epidemiological cohort information should be utilized. By doing this, I wondered if it would be possible to shift the way of understanding disabilities to the viewpoint of an individual’s life course. For that reason, we have proposed the creation of a database of “disability data” necessary for medical welfare intervention effects, and have examined methodologies such as the use of trauma databases [19,20,23]. However, as a related law to this case, in FY 2020, the “Act on Anonymous Processed Medical Information to Contribute to Research and Development in the Medical Field (= Next-Generation Medical Infrastructure Act)” [28], which was implemented on May 11, 2018, went into full-

Table 1: Overview of the three recommendations about the issue “How should we realize self-management for people with disabilities and chronic health problems based on scientific evidence?”

Proposals	Recommendations
1. Necessity to build a registry database “Disability Registry” [19,20,21]	Recommendation No. 1: It is necessary to aim to accumulate data (Author’s note: Use ICF[12] to shift to the perspective of the parties involved, etc.) according to the life course of an individual while linking with trauma databases such as NCD [22] and medical effect databases.
2. Revise the “Definition of Health” in a mature society to a new concept [11,23]	Recommendation No. 2: In a mature society focused on care like Japan, the concept of “Even if people have ‘Social, physical and psychological challenges’ such as acquired or congenital disorders due to trauma or illness, they should maintain their QOL, manage it by themselves, and demonstrate their “what they can do” to achieve self-actualization,” should be added to the definition of health.
3. Human resource development through collaboration with social capital through self-management support programs [24,25]:	Recommendation No. 3: We should aim to develop and disseminate a system that utilizes a self-management support program linked with social capital for all patients and families with chronic injuries/diseases.

scale operation.

In Japan, there is a wealth of medical information under the universal health insurance system. However, medical information is distributed and held, and it is necessary to stimulate the utilization. This is because medical institutions are mainly private, and medical insurers are separated. It was necessary to develop a system to “collect” and “connect” medical information to contribute to research and development in the medical field. Utilization of medical information requires input (information on the implementation of medical treatment) and outcomes (information on the results of medical treatment). The information of the receipt (medical treatment fee statement) has already been made into a database, but it is only input information and does not include much outcome data. The Next Generation Medical Infrastructure Act was enacted because it was necessary to establish a system that contributes to research and development in the medical field by utilizing medical information including results such as medical records.

The Act stipulates, for the anonymous processed medical information that contributes to research and development in the medical field, the authorization of the person who conducts the anonymous processed medical information creation business, and regulations regarding the handling of medical information and anonymous processed medical information. This aims to promote advanced research and development related to health and medical care and the creation of new industries, thereby contributing to the formation of a healthy and long-life society.

We have so far proposed to build a “disability database” by accumulating “prognosis (outcome) information of trauma medical care [19-21].” In other words, the proposal is to integrate information on rehabilitation medical care and nursing care services, medical welfare and nursing care information of local government administrations to obtain outcome information, and evaluate the effects of medical welfare interventions as a “disability database.” For example, information on stroke medical treatment and the “Head trauma data bank” of the Japanese Society for Neuroinjury [29], may be combined with rehabilitation medicine and nursing care data to approximate evaluation of disabilities such as higher brain dysfunction.

How about calling for the integration of various clinical effect databases such as NCD [22], providing medical information regardless of industry, academia, and government, and contributing to the formation of a healthy and long-life society by enhancing the system? Accredited operators of the law plan to collect data, including outcome information, flexibly responding to various medical research and development needs, as part of the “Data utilization platform in all Japan” to prepare for full-scale operation from FY2020. In addition, it was thought that the publication of data analysis results should be speeded up by more efficient and effective online publication, such as promotion of contribution to open journals (Web).

Conclusion

To achieve “revival of rights” and “reconstruction of lives” that are the principles of rehabilitation in the community, where patients/other parties with chronic injuries such as persons with disabilities leave the protected environment such as medical institutions and accept diseases and disorders [30], it is import-

ant for a healthy and safe independent life to support self-help and mutual support. Today, efforts to treat chronic diseases have spread to countries around the world, including developed countries, and are being independently developed [31,33].

In 2020, the new coronavirus infection (COVID-19) is prevalent worldwide. The “new way of life” required of people in COVID-19 is probably how they live in a “society in vulnerability (persons easily to be infected).” In COVID-19, many must have “forced inconvenience” and “experienced unreasonable emotions.” However, this “inconvenience” and “irrationalness” are probably the “physical and mental challenges” that many people with chronic injuries/diseases already had before “corona.” Prejudice and discrimination have historically frequently occurred not only to patients with infectious diseases but also to persons with disabilities and patients with chronic injuries/diseases. We hope that in the future, Japan will build the foundation of a local community where all residents can coexist by making judgments based on scientific grounds without being bound by preconceptions or stereotypes.

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