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Commentary

A Suggestion to Promote Public Health Activities in the Mature Society of Japan. For Establishment of a Self-Management Support System

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Introduction

Why a self-management support system needs to be established

“It is essential for the mature society of Japan to establish a quality self-management support system for people with post-traumatic sequelae and other disabilities”. This concept comes from our years of experience as doctors to follow up the long-term prognosis of a patient with a severe traumatic brain injury (TBI) that occurred in her youth [1-5]. This patient (a woman age 58) suffered a traffic injury at age 16, resulting in multiple traumas that included TBI (coup injury to the right anterior temporal lobe, countercoup injury to the left occipital lobe, and basilar fracture), femoral fracture, and injured knee ligament, forcing her to live with sequelae, multiple disabilities, and various other disorders. Later on, she became a doctor and continued working while experiencing marriage and child rearing; we have observed her from a clinical and public health perspective. When studying at medical school, this patient took a neurosurgery class and learned pessimistic epidemiologic data about the long-term prognosis of TBI, which made her despair that the remainder of her life would be limited to about 20 years. But later, as a doctor, she examined the data that are the basis for the pessimistic long-term prognosis, and found that almost all the epidemiologic data used as the basis for the long-term prognosis of TBI came from the CDC in the United States, whose cases were mostly based on penetrating traumas. This patient also points out a problem that Japan, characterized by an overwhelming number of TBI cases resulting from blunt trauma, lacks a multidisciplinary system that accumulates long-term prognosis data of trauma patients. Over the course of her life, the patient lived through her physical and mental disorders by employing “self-management” arranged from her medical perspective. Through her efforts, she came to question that Japan may be relatively short on social support for self-management for people with sequelae, disabilities, etc. compared to that for healthy people.

According to the Ministry of Health, Labour and Welfare, in recent years there are an increasing number of people with physical or mental disabilities. The total number of disabled people (children) in Japan is 9.366 million, representing approximately 7.4% of the total population [6]. The overall number of disabled people has been increasing, while there are also a growing number of handicapped people using home care or day care services. At the same time, people with disabilities have faced

an aging crisis as well [7]. Since the International Year of Disabled Persons in 1981, in Japan there has been a demand for implementing policy measures to promote an inclusive society where “full participation and equality” can be achieved. From the standpoint of “shift to a sustainable social system”, it is necessary to embody measures that promote the Cabinet Office’s 4th Basic Program for Persons with Disabilities. In this context, specific measures need to be taken to promote disability health and welfare policies for the disabled living independently in a manner that the policies are implemented seamlessly and equally in the community-inclusive care system, regardless of fields and targets. Not limited to traumatic sequelae and disabilities, a number of people in many advanced nations recently have become able to work and go about their daily lives with various chronic diseases as a consequence of changes in disease structure and social situations surrounding health care systems. The increasing number of patients with chronic diseases and impacts associated with this has increasingly become a problem not only in advanced nations, but also in developing countries [8]. As chronic disease measures, disease prevention and medical care for patients with chronic diseases are future critical issues in the health care and public health fields [9]. Japan is no exception in this regard. The following is known about chronic diseases: (1) cerebrovascular disease (apoplexy) accounts for 18.4% of the main cause of why people requiring caregivers needed nursing care, which is the highest rate after dementia, with 24.8% [10], and (2) sequelae will occur even if the patient’s life is saved, meaning that chronic diseases can have significant impact on decline in QOL [11,12]. In order to make an active discussion on future ideal public health policies and transition measures, we believe that establishment of a quality self-management support system should be considered in Japan for people with disabilities, sequelae, chronic diseases, and various other health-related chronic disorders (hereinafter called “chronic health problems”); consequently, we have made suggestions necessary to achieve the objective.

Three Suggestions Necessary to Establish a Quality Self-Management Support System for People with Chronic Health Problems

Establishment of a “disability registry (database) (broad sense)” and better information accessibility

The basic strategy of the Healthy Japan 21 initiative [14] in the Basic Direction for Comprehensive Implementation of National Health Promotion (Ministerial Notification No.195 of the Ministry of Health, Labour and Welfare of 2003) is intended to reduce the number of early deaths and disabilities, extend the period of healthy life without any disabilities (healthy life expectancy), enable individuals to live out their productive and satisfying lives, and achieve a sustainable society. The basic process to achieve this is the evaluation of health improvement potential and intervention effectiveness by setting goals (values) and assessing achievements; to do so, it is essential to collect, accumulate, and utilize information. Trauma can be the main cause of sequelae and acquired disorders; thus it is necessary to collect and accumulate information on health care needs of post-acute medical care in the “care-focused mature society” proposed by Tachibana et al. (as described in detail in II-3), while the Health Care 2035 initiative [15] points out the significant lack of such information in Japan. Based on our belief that a collaboration database for trauma prognosis (outcome) information needs to be built as health information infrastructure for a mature society, we have explored possible ways to achieve the objective in Japan [3-5,16]. As the significance of accumulating and utilizing the trauma prognosis information regarding the head, etc. it is possible to (1) reexamine the advantage of including a public health approach in the disability health and welfare policies, as well as to (2) rethink disabled people from their perspective as citizens by conducting an epidemiological longitudinal study; thus, we also highlight the advantages that this initiative can lead to re-evaluation of policies for persons with disabilities and even contribute to promoting disability health and welfare policies [17]. At the same time, in terms of better information accessibility, we suggest that it also be considered that the accumulated data

may possibly be utilized by patients (the persons concerned) as a basis to determine the exercise of their right to self-determination when they are independently engaged in health promotion activities. Based on these concepts, we made a policy proposal for the scheme of a health care, nursing care, and health welfare database (broad sense) “Disability Registry” for injuries, diseases, and disabilities (Figure 1) [18,19,20].

Definition of health for a mature society

In regard to the word “health,” the WHO Constitution of 1948 defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity; the definition was translated literally into Japanese as well. Later, the WHO made a new proposal in 1998 that health is a dynamic state of complete physical, mental, spiritual, and social well-being and not merely the absence of disease or infirmity. The Executive Board adopted the proposal to the General Assembly, although it was suspended at first without deliberation. Machteld Huber et al. [21] argue that the WHO’s definition of health as “complete well-being” no longer serves the purpose due to the increasing number of chronic diseases, and proposed to shift the emphasis to “the ability to adapt and self-manage in the face of social, physical, and emotional challenges”.

The new definition of health was also deliberated in Japan, while the discussion became sluggish since the words “dynamic” and “spiritual” in the WHO’s new proposal could not properly be translated into Japanese; for this reason, the definition of health adopted in 1948 is used even today [22]. However, even in Japan, the trend in health has significantly changed compared to that in 1948. The Healthy Japan 21 initiative defines “healthy life expectancy” as “the period of healthy life without any disabilities”. However, humans may, as healthy

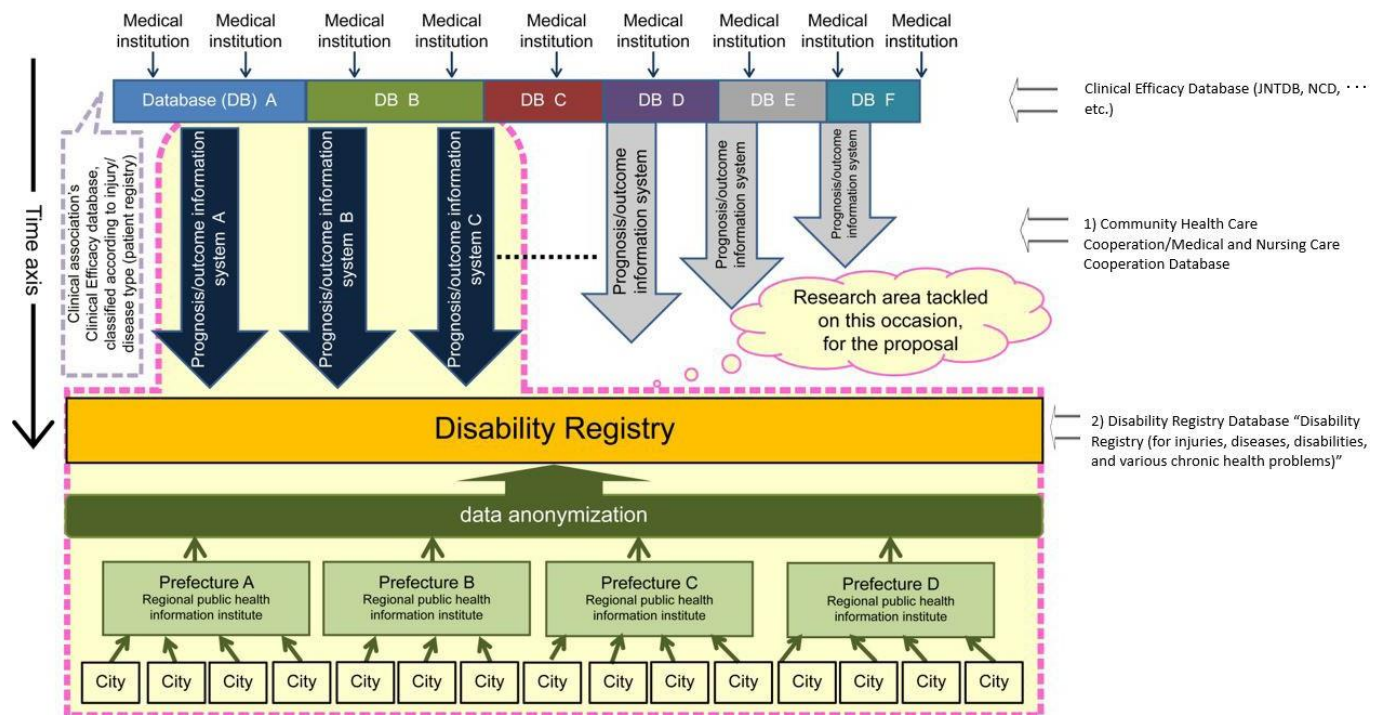


Figure 1. Conceptual diagram of the proposed “Disability Registry (Broad sense)”: Disability Registry (for injuries, diseases, disabilities, and various chronic health problems) consists of a regional medical collaboration/medical care collaboration database and “Disability Registry (narrow sense)”. ([20], Figure 4). Diagram representing the study on the regional model development of the “Injuries/Diseases Medical Treatment, Nursing, Health, and Welfare Database”. Authors made some modifications].

life expectancy extends, face various physical, mental, and social challenges in the course of their diverse lives. In consequence, some may be forced to live with various sequelae, disabilities, or chronic diseases for the rest of their lives (in the case of people with congenital diseases, from the starting point of their lives). We think that it is reasonable to shift the concept of health toward “the ability to adapt and self-manage”, even under such circumstances, as the definition of health in a care-focused mature society. Based on our belief that “New Definition of Health-Japanese Version” for the Health Care 2035 initiative should be necessary to address the problem that the conventional definition of health, “complete well-being”, seems to eliminate people with disabilities or chronic diseases from the concept of health, Tachibana et al. proposed “Definition of Health for a Care-Focused Mature Society” for the future mature society of Japan (Table 1)[23].

Table 1. Definition of Health for a Care-Focused Mature Society [13].

Definition of Health for a Care-Focused Mature Society
In a care-focused mature society such as Japan, the notion that “despite social, physical, and mental challenges” such as the disabilities acquired from trauma or disease, quality of life can be maintained and that one “is able to self-manage” and aim for “self-actualization” should be added to the future definition of health.

Establishment of a quality self-management support system for people with chronic health problems for better human support working with assistive technology of things

An inclusive society is a society where the disabled, etc. who could not always be fully involved in their community, can actively dedicate themselves in social participation and contribution [24]. After the UN Convention on the Rights of Persons with Disabilities (hereinafter called the “Convention on the Rights of Persons with Disabilities”) was adopted in 2006, the Basic Act for Persons with Disabilities (Act No. 84 of 1970) was revised in 2011 in line with the enactment of the Convention in 2008 [25]. Article 1 of the act stipulates that an inclusive society is a society where, in accordance with the principle that all citizens, regardless of whether or not they have a disability, should be entitled to dignity as irreplaceable individuals enjoying fundamental human rights, no citizens are divided according to whether or not they have a disability for coexistence with mutual respect for personality and individuality [26]. Inclusive society is a participatory society where the diversity of individuals is mutually recognized. The Basic Act for Persons with Disabilities and the Act for Eliminating Discrimination against Persons with Disabilities (Act No. 65 of 2013) (hereinafter called “Disability Discrimination Act”) stipulate the responsibilities of “promoting the policies for supporting the independence and social participation of persons with disabilities” and “citizens’ duty to strive to achieve an inclusive society”. In Japanese society, where the values and personalities of individuals have been diversified with an increase in the number of foreign residents and the coexistence of various generations due to extended healthy life expectancy, achieving an inclusive society is regarded as one of the priority

issues that should be addressed first and foremost.

What is important is that environmental improvement measures to achieve such an inclusive society are enhanced by ensuring a good balance between assistance utilizing things (assistive technology, etc.) and human support. The foregoing proposal of the “better information accessibility” can be defined as a “measure for a better support environment utilizing things”. In addition, measures for enhancing the human support environment also need to be taken; Tachibana focused on Self-Management Education (SME) as a methodology to achieve this. SME is defined as “teaching patients (with chronic diseases) the task-management skills so that they can take appropriate actions to become healthy from their own perspective” [27]. Comparing the patient education that has conventionally been provided in the Japanese community health care field to SME, in the former case, self-management-related issues and challenges are defined by health care professionals, etc. in a disease type-specific manner, and the management skills and information are also offered by health care providers. On the other hand, in the latter case, or SME, self-management-related issues and challenges are defined by patients themselves, and patients are independently involved in acquiring the management skills and information. In other words, SME (1) assists patients in making decisions and actions for solution of self-management-related issues and (2) provides them with skills to take appropriate actions that are still helpful even if the environment surrounding them is changed. For this reason, SME is defined as a complement to (conventional) patient education.

Among SMEs, the Chronic Disease Self-Management Program (CDSMP) [28] developed by Stanford University in the United States in the late 1980s is one of the most popular programs, available in 22 countries worldwide today. CDSMP is characterized by the following advantages: (1) it is easily accepted by participants (including patients and their families) because two leaders including at least one nonprofessional patient lead the program and it can be conducted at an affordable cost, (2) mutual interaction among participants becomes active, and (3) people with all kinds of chronic diseases, including rare diseases, can be covered, since there are no limitations on the types of diseases [29]. The mechanism for the effect of CDSMP includes the improvement of (1) self-management skills and (2) self-efficacy, while (2) improvement of self-efficacy is important to make the program more effective [30-32]. Furthermore, CDSMP is a well-established methodology backed up by many assessment studies, including randomized-controlled trials [33]. The program is reported to have various benefit verification results, including enhanced self-efficacy, improved physical disability functions, and reduced frequency of visiting medical institutions. Based on these outcomes, Tachibana proposed the utilization of SME in establishing the health promotion support system for the disabled [34] and the necessity of human resource development [35] for the sake of reform in the Japanese disability health and welfare policies. Tachibana also focused on the CDSMP’s methodological characteristics and proposed to strengthen the collaboration between academics and practice in the Japanese public health field through promoting the CDSMP-based self-management support measures for people with chronic health problems (Figure 2) [36].



Figure 2. Image of an environment that supports health for all (Quoted from Ref. 34.) **Figure 1.** Image of an environment that supports “Health for All” (Quoted from Ref. 13.) Image of regional health promotion system in mature society* proposed by Tachibana et al. *We defined mature society as “a society that aims at matured death by preventing premature death [13]”. ©Tachibana T. Center for Public Health Informatics, National Institute of Public Health.

For Promotion of Future Public Health Activities in the Mature Society of Japan

In the 1990s in Britain, the work hours of health care professionals needed to be significantly reduced due to work-hour regulations introduced to EU member countries. Around the same period, various measures for health care professionals were also taken under severe financial circumstances, such as developing a professional education system and employing foreign workers, in order to make qualitative and quantitative improvements in, and ensure sustainability of, the exhausted health care services. In the major reform, where health care professionals were increasingly involved in prescription and other medical practices and new ancillary positions were established, self-care was promoted as part of the NHS Constitution’s principle “patients and citizens also take part in changing the system” [37]. On the other hand, Japan’s demographic structure is expected to change from rapid aging of the population to radical decrease in the working population by 2040. The Ministry of Health, Labour and Welfare is currently deliberating concrete measures and system reforms to address social security reform, even in view of that demographic shift [38]. In other words, future ideal public health policies and transition methods are now being discussed in contemporary Japan, whose national literacy rate is high and whose educational system is also well-established. In order to explore the sustainability of health care services and the possibility of methodologies that contribute to social security reform with a view to future ideal public health policies and transition methods, we propose promoting the establishment of an SME/CDSMP-based quality self-management support system for people with chronic health problems.

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