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Minireview

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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Abstract

This study presents a strategy focused on addressing chronic health problems. The author continued to feel the need for social support for self-management of chronic injury patients and their families through the experience of severe trauma. Then I made three proposals based on a personalized logically approach as follows: (1) Establishment of a “Disability Registry Database (including various chronic health problems)” and improvement of information accessibility, (2) Disseminating Definition of health for a mature society, and (3) Establishment of a quality self-management support system for people with chronic health problems. Through the cases/experience of Britain in the 1990s, the main medical issues in Japan were “accumulation and utilization of data” and “analysis of fairness,” and the author seemed to present a plan to solve the issues. With the declining birthrate and aging population, changes in disease structure, and growing and diversifying health care needs under sound finance, a paradigm shift will be necessary to maintain a healthy level. I would like to make a proposal to move from the model of cure to that of care through this study.

Keywords: chronic health problems, disability, chronic disease, self-management, care model

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 the author’s years of experience as a doctor to follow up the long-term prognosis of me with a severe traumatic brain injury (TBI) that occurred in my youth [1-5]. The author (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 ligaments etc., forcing me to live with sequelae such as blindness in the right eye, multiple disabilities, and various other disorders. Later on, I became a doctor and continued working while experiencing marriage and child rearing; I have observed me from a clinical and public health perspective with my husband of a medical doctor. When studying at medical school, I took a neurosurgery class and learned pessimistic epidemiologic data about the long-term prognosis of TBI, which made me despair that the remainder of my life would be limited to about 20 years. But later, as a doctor, I 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 in Japan came from the CDC in the United States, whose

cases were mostly based on penetrating traumas. I also pointed 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 my life, I lived through my physical and mental disorders (e.g. Hashimoto disease, depression, lung cancer, thyroid cancer and collagen disease etc., and 12 times of operations), by employing “self-management” arranged from my medical perspective. Through my efforts, I came to question that Japan may be relatively short on social support for self-management for people with sequelae, disabilities, and other various chronic conditions 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.

Approach

The author has described three main objectives that are based on the logic of the problem as the below.

Establishment of a “Disability Registry (Database) (Broad Sense)” and Better Information Accessibility

In the following, “disability” will be used as a general term for “sequelae, disability, chronic disease” unless otherwise specified. 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) [18-20].

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 life expectancy extends, face various physical, mental, and social challenges in the course of their diverse lives. When some kind of trauma occurs, the sequelae or disabilities may remain, and in the case of disaster or crime, the trauma of the mind (e.g. Post Traumatic Stress Disorder: PTSD) may remain. 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

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-Man-

agement 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 1] [36]. However, the policies and systems surrounding health and welfare and medical care vary from country to country. Therefore, in order to support self-management for each illness, I thought that it would be necessary to develop a program according to the targets of the patient area, and we conducted a development and evaluation study of a post-stroke self-management support program [37].

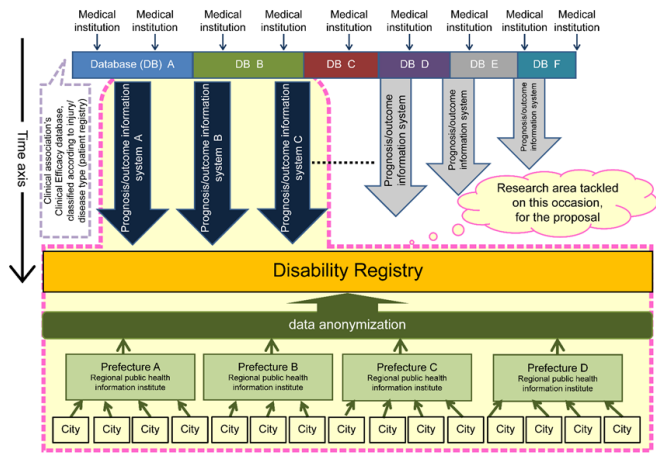


Figure 1. An image of the medical welfare database for people with chronic conditions [36].

References to cases / experiences outside Japan Overseas medical system

Knowing overseas cases and experiences of related topics will help us to think about what kind of situation Japan’s policies can be in the future. This chapter mainly gives an overview of the medical system in Europe, which is an aging continent with associated chronic health problems that has related strategies. Especially I mention the United Kingdom since the 1990s, and explores hints for Japan.

In the UK, since 1948, free medical services have been provided through a system called the National Health Service (NHS), which is mainly financed by taxes [38]. For the use of the NHS and the use of hospitals (secondary and tertiary medical institutions), it was necessary to be referred a registered family doctor (GP), except in case of emergency. In 1979, the NHS reform was implemented in Britain in line with Thatcher’s appointment as prime minister by controlling the finances under the Conservative government. Both the quantity and quality of medical services declined, and the problem was that the waiting time before consultation was extended. At the same time, the adoption of the European Working Time Direction by the EU (1993) also led to a significant reduction in working hours for medical professionals [39, 40]. In 1997, a new Labor Party leader, Blair, launched with a slogan of “Third Way [41],” released a white paper evaluating the Labor Party’s regime for the NHS reform [42]. They were collectively represented by the slogans of “from the internal market to integrated care” and “from competition to partnership.” The difference between the Blair administration, which used New Public Management [42] as the framework for the NHS reform, and the Conservative administration, was considered to be “emphasis on quality” and “emphasis on justice [43].” “Efficiency” was kept also by the Blair administration following Thatcher’s Conservative government, but a mechanism to improve quality was created in order not to sacrifice “quality [44].” Hospital operations are now evaluated by the Performance Assessment Framework :PAF, and as one institution that evaluates medical technology from the perspective of cost-effectiveness (= efficiency), the National Institute for Clinical Excellence: NICE was established. Since 1971, epidemiologist Cochran has put forward the idea of medicine based on the evidence that “information on the effectiveness of prevention, diagnosis, and treatment methods should be accumulated and only effective

ones should be implemented.” Cochran’s assertion that “the focus should be on the results of randomized controlled trials (RCTs) without bias, rather than on the basis of observational expert opinion,” had been contributed to the establishment of the NICE [45]. Furthermore, the standard framework that medical services should reach based on the EBM was presented as the National Service Framework: NSF.

In addition, the NHS reform under the Blair administration emphasized “fairness” and “equality” and did not tolerate widening disparities due to competition or regional disparities. “Health inequality” seemed to be a problem that existed before the Blair administration. It is said that the Conservative government’s attempt to silence a report submitted to the government in 1980 by Lord Black, the chairman of the Royal Medical Association, who was appointed chairman of the Committee on Health Inequality established by the Labor government in 1977. However, criticism aroused from the journalism and medical circles, became a topic book on the contrary, and was published as a general book [46]. The content of the report was shocking, and the establishment of the NHS revealed that the mortality gap by class was rather widening, and interest in the issue of “health inequality” began to grow after the Black Report. The Blair administration confirmed that “health inequality” has not diminished, and an action plan has been published in response to the proposed policy challenges [47,48].

As described above, in the 1990s in Britain, 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” [40].

The proposal to move from the model of cure to that of care

Kondo derives “lessons for Japan” from the history of British medical reform and an analysis of the comparison of the medical systems in Japan, Britain and the United States [49,50]. According to his report, first, “the degree of progress and accumulation of medical service research that studies the quality and efficiency of RCTs and medical services that form the basis of EBM” is a suggestion for Japan. And he pointed out that “behind the lack of accumulated medical service research, which is essential for improving the quality of medical care, is the lack of data and lack of availability due to the lack of investment in information technology.” In addition, Kondo said: Regarding “health inequality,” it is said that even in Japan, income disparities (Gini coefficient) and disparities between social strata have widened since the 1980. It will be a public health challenge.

Our research [51] aims to build an information infrastructure that solves such weaknesses which Kondo pointed out. This is because the regional model which will be constructed as a result is expected to develop into a database that does not limit information storage or use to specific diseases. Furthermore, in the plan, for the data to be accumulated, the “existing database”

in which data is already accumulated by various subjects and disease names will be used, and the regions will take the initiative in attempting to combine the databases. Therefore, it is considered that a large-scale database can be constructed at a relatively low cost, and it can be an advantageous process in terms of cost performance. Moreover, if a database of “disabilities” is constructed in accordance with the development of the regional model, it will be easy to translate the strategies for people with disabilities from “diagnosis name to care needs.” Not only that, but it will also be possible to add “obstacles” to the subjects that examine the existence of health disparities between fields. In the future, the “comprehensive community care system” to be implemented in 2025 will require care that does not cause disparities or discontinuities in different areas. The first target “disability” of the regional model in the plan is “the field where the longitudinal epidemiological data is currently insufficient.” Therefore, this plan will have the advantage of contributing to the enhancement of the regional comprehensive care system. The above-mentioned overseas experiences and cases seemed to support the validity of our proposals as a realization measure.

In Japan, it is expected that health care needs will increase and diversify, and the necessary resources will increase, in line with the aging population and changes in the demographic structure, such as the declining population [52]. By 2035, the baby boom junior generation will begin to reach the age of 65. In 2035, it is expected that socio-economic conditions and lifestyles will continue to undergo major changes in many countries around the world. Even in many developing countries, the center of illness structure will shift from infectious diseases to non-infectious diseases by 2035, and the level of health will approach that of developed countries, and will face the challenges of aging [53]. In Japan, where the aging of society is ahead of the world and the challenge of coping with a declining birthrate and an aging society is an issue, a new vision for health measures has been announced to further develop and lead the maturity of the world in anticipation of 2035. (“Healthcare 2035”) [54]. “Healthcare 2035” is “In order to realize a healthy society in which each and every person can play a leading role, in order to contribute to economic growth and financial reconstruction, and to realize a healthy society in the midst of drastic changes in the environment surrounding health care, it is becoming necessary to change the way the system works.” In recent years, with the development of medical technology and changes in disease structure, people who live in society while having health problems and disorders during the chronic phase due to various injuries such as after the completion of acute medical care for chronic diseases and trauma is increasing. In order to realize a sustainable health care system that enables the people to have peace of mind and satisfaction, this study would like to propose to “move from the model of cure to that of care” as a health planning initiative.

Conflicts of Interest

There is no Conflicts of interest that need to be disclosed in regard to this paper.

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