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Minireview

Promotion of Evidence-Based Health and Welfare Policies for People with Disabilities in Japan-Proposing to Apply Self-Management Education for Switching to the "Health Promotion System for a Care-Centered Mature Society, that Does Not Leave Anyone Behind"

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Abstract

This study examined the methodology to realize our previous proposal to promote evidence-based health and welfare policies for all, including people with disabilities in Japan. First, this study outlined the proposal: 1) Promotion of use of the Clinical Efficacy Database, and 2) The definition of "health in a care-focused mature society." Second, I reviewed self-management education (SME) and "Chronic Disease Self-Management Program (CDSMP)" to examine whether they had possibility as methodology to promote the Japanese health and welfare measures for people with disabilities. CDSMP was thought to be able to apply to health and welfare measures for people with disabilities of local governments, from the view point of methodologies, features, effects etc. This study concluded that, 1) CDSMP should be applied to the Japanese health and welfare measures for people with disabilities for promoting the measures, and 2) Promotion of human resource development necessary for that was thought to be one of the new challenges.

Keywords: evidence-based health and welfare policies for people with disabilities, self-management education (SME), chronic disease self-management program (CDSMP), health promotion system for that does not anyone behind

Introduction

In recent years, with the change in the structure of diseases and the change in social conditions surrounding medical care, many people come to work and live their daily lives while having chronic diseases. The increasing number of chronic disease patients and the consequent effects have become a problem not only in developed countries but also in developing countries [1]. Not only prevention but also care for chronic disease patients has become an issue in health care and public health as measures against chronic diseases [2].

Looking at the demographics of Japan, it is predicted that the growth of the elderly population will be rapid until 2025, when all the so-called baby boomers are over the age of 75, but will be moderate thereafter. On the other hand, the working-age (15-60 y.o.) population, which has already started to decline, is expected to accelerate further decline from 2025 [3]. Therefore, if we look at social security and working style reform in anticipation of about 2040, a fundamental productivity improvement policy will be necessary.

Drastic reforms in healthcare are required in Japan [4]. Japan's current vision is to further develop healthcare and lead the world as a maturing nation. "Japan Vision: Healthcare 2035" [5] aims to achieve a paradigm shift toward "care-centered healthcare," "quality improvement," "patient-centered values," "discipline by concerned parties," and "integration" by 2035.

Under such circumstances, it became clear that "the Former Eugenics Protection Act (1948-1996), which was enacted after the promulgation of the Constitution of Japan (1947-), forced infertility surgery had been performed on many people with disabilities" in recent years. It turned out that "reproductive rights" of the people with disabilities were found to have been taken away, and the media reported that "Constitutional judgment was made against past forced infertility surgery." [6] Reproductive rights are one of the basic human rights. "Respect for basic human rights" is one of the three principles in the current Constitution of Japan, along with "National sovereignty" and "Peace principle," and they are human rights that people are born with. The essential rights for human beings are to be "respected as irreplaceable individuals, treated equally, and to live freely in accordance with their own will." We have to say that there is still room for improvement in Japan's policy for people with disabilities. Therefore, we should never forget the point of view of "policies that do not leave anyone behind," in the dramatic reforms in healthcare from now on.

First, this study outlines the measures we have identified and proposed through Japanese policy review for promoting evidence-based health and welfare policies for people with disabilities (Figure 1) [7,8]. Second, this study reviews the methodology that supports self-management of people who have chronic conditions, on a daily basis. And, I will consider the approriateness of SME as a methodology for improving the health and welfare policy of people with disabilities in Japan.

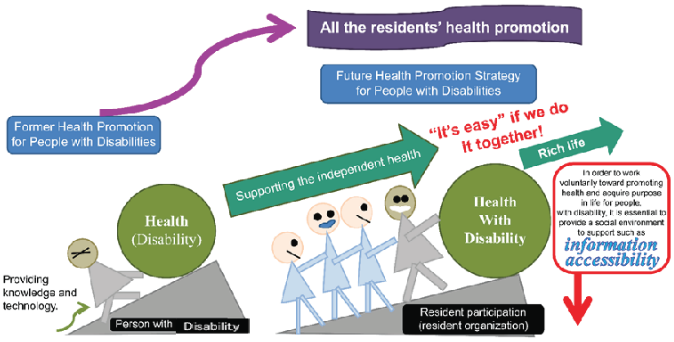

Figure 1. Image of an "environment that supports health" for people with disabilities.

Concept of the Policy for Promoting Evidence-Based Health and Welfare Policies for People with Disabilities

Promotion of use of the clinical efficacy database

In Japan, Evidence-Based Health Policies (EBHPs) have been promoted for lifestyle diseases, and the information necessary for EBHPs for cancer countermeasures is accumulated in the "Cancer Registry" and utilized by medical institutions and public health centers according to law. Evidence such as survival rates of cancer is useful not only for healthcare providers and policymakers, but also for cancer patients in executing the right to self-determination in promoting health.

Meanwhile, epidemiological statistics on trauma are limited to "patient registration at the onset of injuries and illnesses" presently; hence, evidence regarding the long-term outcomes of trauma in Japan is overwhelmingly lacking. In Japan, since the 1960s, the number of injuries and deaths from traffic-related trauma has increased rapidly along with the rate of emergency care [9]. With such changes, the estimated number of "those with sequelae and disabilities acquired from trauma" has increased. The incidence of trauma is estimated to be comparable to that of neoplasms in the 2014 national patient survey. We viewed trauma prognoses in terms of "acquired disability outcomes," and proposed reviewing the healthcare and welfare measures for people with disabilities in a longitudinal epidemiological study to "understand the disease from the viewpoint of the concerned party as a living person" [10-13].

To realize this view in a care-focused society, we focused on the Clinical Efficacy Databases, which contain information related to diagnoses, treatment process, treatment efficacy, etc., of patients examined and/or treated at all medical institutions in Japan. These databases are usually developed by academic clinical associations categorically based on disease/injuries [14,15]. However, the bulk of each comprises registry information of patients classified by disease/injury. To evaluate the clinical efficacy of such databases, it is necessary to assess the outcomes through a follow-up study. However, it is currently difficult to perform a satisfactory assessment of outcome information.

The Definition of "Health in a Care-Focused Mature Society"

In Japan, all citizens are guaranteed access to necessary medical treatment by the National Health Insurance System (= universal health coverage) [16]. However, due to societal aging, difficulties related to the state of public finance continue, and it is necessary to invest the scarce resources efficiently. To help achieve this, we focused on accumulating information for evaluating clinical effects as part of the movement for a sustainable health policy for people with disabilities. As one achievable outcome information area, we proposed the establishment of a disability registry database ("Disability Registry"). [7] Currently, it is compulsory for local governments to control information related to the health and welfare of people with disabilities, such as information in the "Certification for Persons with Physical Disabilities" using a logbook. It is the responsibility of prefectural governors and mayors of cities, but these parties have not yet made full use of such information for purposes such as analysis and evaluation of health policies for people with disabilities. Therefore, we have proposed studies based on the proposal that each prefecture collects and stores this information within the jurisdiction of its respective city. These data are anonymized in each prefecture and stored in the "Injuries/Diseases Health and Welfare Database," which we are proposing as "Disability Registry." In the context of this proposal, in the future, we should proceed with studies on the regional model development of the "Injuries/Diseases Medical Treatment, Nursing, Health, and Welfare Database."

In 1948, the WHO charter defined "health" as "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity." Since 1948, this definition has continued to be used in Japan. However, the global trends in health have changed greatly since 1948. Particularly, the concepts excluded from this definition of health, such as disabilities, are not reflected in the health policy of Japan. So we have proposed the "Definition of Health for a Care-focused Mature Society." (Table 1) [17].

Table 1. "Definition of Health for a Care-focused Mature Society" [7,17].

In a care-focused mature society such as Japan, the notion that "despite 'social, physical, and mental challenged' 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"."

A Review of the Methodology that Support Self-Management of People who have Chronic Conditions

Self-management education (SME)

The global burden of disease is shifting to long-term conditions [18], and there is world-wide interest development of models of service delivery to manage these changing needs [19]. People have to manage their own health on a daily basis (= self-management). Whether one is a healthy person or one with chronic conditions, they must engage in their own self-management. In particular, people who live with chronic diseases are forced to do their self-management work on a daily basis, sometimes leading to life restructuring, and in line with real life and their own views of life. As a result, self-management of people living with chronic diseases often involves great difficulties. Therefore, the importance of supporting self-management is increasing, and support by SME is required.

In recent years, with the accumulation of research on chronically ill patients and on QOL, "SME" to support self-management of people living with chronic diseases has been spreading mainly in Western countries. The term "self-management" began to be used in the childhood asthma program in the mid-1960s [20]. Traditionally, the course of the disease in chronic disease was thought to be mainly due to physiological changes. However, it has been suggested that people with chronic diseases may also have illness in the psychological foreground perspective [21]. From this point of view, SME is "teaching task-solving techniques so that patients can take appropriate actions to be healthy from their own point of view"[22].

Since the era of acute diseases, self-management support has been provided in the form of "patient education". In the case of patient education, the medical staff defined the problems in the patient's self-management in a disease-specific manner, and the medical staff provided the technology and information for solving them. In SME, on the other hand, patients themselves define their own problems / tasks. SME assists the patient in making decisions and actions for resolution, as well as providing technology that enables them to take appropriate action even if the environment surrounding the patient changes.

Therefore, SME can be regarded as a complement to patient education. As a result, the following two points are expected in SME: 1) Acquisition of the ability of patients themselves to mobilize their self-management techniques and information, and 2) Motives to appropriately cope with physical, psychological and social problems, and problems caused by chronic diseases.

The Chronic Disease Self-Management Program (CDSMP)

Among the SME programs, the Chronic Disease Self-Management Program (CDSMP), which was developed at Stanford University in the late 1980s, is currently offered in 22 countries worldwide. It is now one of the most popular programs in the world [23].

The goal of the CDSMP is to "make it possible for each patient to be able to spend their sick life and life as they are [24]". CDSMP focuses on the following three tasks: 1) Medical management of the condition: taking medication, adhering to a special diet, using an inhaler, etc., 2) Management of social life: maintaining, changing, and creating new meaningful behaviors or life roles etc., and 3) Management of emotion: coping with emotional sequeli of having a chronic condition (anger, fear, depression, etc.), which alters one’s view of the future [25].

The CDSMP is implemented six times for a total of six weeks, with two and a half hours once a week as one session.

It is conducted in a workshop format and progressed by two leaders. At least one of the leaders is a patient with chronic disease. The number of trainees is basically 8 to 16 and includes chronic disease patients and family members of chronic disease patients. The workshop will include weekly lectures by the leader, practical training by the participants themselves, such as weekly goal setting and result reporting, problem solving techniques, relaxation techniques and exercises, food management, and communication with family members and healthcare workers. Participants learn through discussions and brainstorming with each other [26].

As features of CDSMP, the following three can be mentioned: 1) Non-professional patients advance the program as a leader. As such, it is easy to accept, persuasive, and cheaper than offered by experts. In addition, it can be expected to have almost the same effect as provided by the experts, 2) Interaction among participants is active. Therefore, an effect similar to the self-help group is expected. It is possible to acquire observation learning opportunities and experience knowledge, and 3) as it does not limit the disease, so can be generally targeted at people with chronic disease. Therefore, it is easier to recruit participants than to limit the disease, and can provide information and support opportunities for patients with rare diseases [27].

As the effect of CDSMP, the following two categories can be mentioned: 1) Behavior change leads to self-management technique improvement (= effect of conventional health education), and 2) Improving the feeling of self-efficacy on health status (= more important mechanism of effect development) [20,28,29]. In the effect expression mechanism of CDSMP, the "self-efficacy improvement effect" of the latter 2) is more important for raising the program effect than the former 1).

According to the self-efficacy theory, the following four are the main factors that improve self-efficacy: 1) Achievement of performance actions (ex. action success, achievement experience), 2) Proxy experience (ex. Discussion at patient meeting), 3) Verbal persuasion (ex. support by words and attitudes, trust, encouragement), and 4) Physiological and emotional uplifting and arousing (ex. positive thinking, raising awareness, and solving beliefs).

Lay-led self-management programmes are becoming widespread in the attempt to promote self-care for people with chronic conditions, and the effectiveneess of lay-led self-management programmes for people with chronic conditions were to be assessed [30]. Table 2 shows the main effects of CDSMP, according to the systematic review that integrates the results of randomized controlled trial for changes after six months (Table 2).

Looking at the situation of CDSMP in Japan, to introduce CDSMP into Japan, several patient support groups jointly visited Stanford University in 2004. In 2005, the Japan Chronic Disease Self-Management Association [31] was established, and the first CDSMP workshop was started. Currently, CDSMP is provided annually by the association, and so far, application to various chronic conditions such as allergy, mental health, prevention of recurrence of stroke and myocardial infarction, diabetes and chronic obstructive pulmonary disease (COPD) etc., has been verified [32,33].

Table 2. The main effects of CDSMP, according to the systematic review that integrates the results of randomized controlled trial for changes after six months [26,30].

Effects	Standardized Mean Difference (SMD)	95%CI
Pain reduction	-0.10	-0.17 to -0.03
Improvement of disability/impaired physical function	-0.20	-0.30 to -0.11
Fatigue reduction	-0.15	-0.22 to -0.07
Anxiety improvement	-0.14	-0.25 to -0.04
Improvement of psychological well-being	-0.28	-0.55 to -0.01
Improvement of general/ self-rated health	-0.20	-0.31 to -0.10
Decreased health distress	-0.25	-0.34 to -0.15
Increase in frequency of aerobic exercise	-0.19	-0.27 to -0.11
Increased frequency of cognitive symptom management	Weighted Mean Difference (WMD) -0.32	-0.40 to -0.25
Improvement of communication with healthcare professionals	-0.13	-0.24 to -0.01
Improvement of self-efficacy to manage (ASMP)	-0.26	-0.43 to -0.09

Discussion

In Japan, the universal health insurance system guarantees access to necessary medical care, but since fiscal conditions have been going to be severe due to the recent declining birthrate and aging population, efficient resource allocation is required [8]. As CDSMP can be expected to contribute not only to interventional effects of individual improvement but also to sustainable medical finance, even for the realization of Sustainable Development Goals (SDGs), it would be useful and appropriate as a methodology for making our proposal a reality to improve the health and welfare policy of people with disabilities in Japan.

From now on, it will be a challenge to develop human resources capable of flexibly responding to rapidly changing health problems in accordance with changes in the times with a scientific perspective [34]. In order to disseminate and promote high quality health and welfare measures for people with disabilities by CDSMP, human resources developments of local government officials such as public health nurses are also important and needed.

Concluding Remarks

This study reviewed SME and CDSMP to examine the appropriateness of how to realize our previous proposal to promote evidence-based health and welfare policies for people with disabilities in Japan. SME, especially CDSMP was considered to be useful and appropriate as a methodology for improving the health and welfare policy of people with disabilities. I propose to apply CDSMP in the reform of health and welfare policy of people with disabilities in Japan.

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Conflicts of Interest

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

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